Automated Check-in Data Collection (AC DC): an investigation of utility, acceptability and effectiveness in general practice

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October 2021

Submitted in fulfilment of the requirements of the degree of

Masters of Philosophy

School of Medicine

Keele University

ACKNOWLEDGEMENTS

There are some people who have provided me with great support in undertaking this MPhil. thesis, whom I would like to thank. Firstly, I would like to thank my supervisors, Professor Toby Helliwell and Professor Christian Mallen. They have constantly provided me with support and encouragement and have been on hand, with patience, to answer my queries along the way. In particular, they have provided optimism and confidence in my innovative conceptions, encouraging my work in the optimisation of methodologies to increase research participation. I would also like to thank Dr John Edwards for his friendly support and advice during my first few months, ensuring my direction was focussed.

Special thanks also extend to the wider staff based at the School of Medicine at Keele University who were pivotal in ensuring that my study took place, with the health informatics and regulatory support it required.

I would like to thank the participating general practices that played an essential role in firstly, adding new technologies to their already busy general practices, and secondly for hosting the AC DC Study and its associated research questions. Great thanks in particular, go to Matthew Griffiths who provided me with an endless list of fictional patients (or cartoon characters) and lots of patience, as I tested the data collection methodology, usually during his lunch breaks!

I am extremely grateful to the National Institute for Health Research (NIHR) Clinical Research Network: West Midlands, who without their support, this study would not have been possible.

Finally, I would like to thank my family and friends but especially my parents, who throughout my life have always supported and encouraged me. Then, most importantly, great thanks

go to my husband Carl and my three children Oliver, Laurence and Fiona. Whilst I still leave Laurence perplexed with my fascination of check-in screen capabilities, they have all provided me with un-ending cups of tea, encouragement, love and support which I am truly thankful for.

ABSTRACT

Background: There are a range of data collection methodologies employed for collecting patient health related research data. Within primary care settings, and particularly within general practice, time and resources are limited. The utility of an automated check-in screen to collect brief research data from patients is a new option, that requires investigation.

Methods: A systematic literature search was conducted to identify articles describing the use of data collection methodologies that patients currently use and interact with independently, within primary care settings. A pilot-feasibility descriptive cross-sectional study was then undertaken to investigate the utility of check-in screens and to collect brief research data from patients, whilst they self-completed an automated check-in screen, prior to their appointment.

Results: Limited evidence exists in health literature relating to the collection of research data using automated devices, within primary care settings. 9,274 participants were recruited to the **A**utomated **C**heck-in **D**ata **C**ollection (AC DC) Study from 9 general practices over a 3-week recruitment period. Almost 90% of all patients presented with the opportunity, participated in the study. 96.2% of participants answered the 'clinical' research question, reporting a degree of bodily pain experienced during the past 4 weeks. The severities of pain reported were comparable with results identified elsewhere. 89.3% of participants answered the 'non-clinical' research question, on happiness to be contacted about future research studies.

Conclusion: Choosing which data collection method to use when conducting research, remains a predicament for researchers. Using automated check-in facilities, to integrate research into routine general practice is an efficient and effective way to collect brief

research data from patients, with no variation by age of patient. With the COVID-19 pandemic initiating an extensive digital transformation in society, now is an ideal time to investigate other ways in which electronic research data can be captured quickly and efficiently.

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LIST OF ABBREVIATIONS

AC DC	Automated Check-in Data Collection
CCG	Clinical Commissioning Group
CPRD	Clinical Practice Research Datalink
CRN	Clinical Research Network
CRN WM	Clinical Research Network: West Midlands
DNA	Did Not Attend
EMIS	Egton Medical Information Systems
EU	European Union
GDPR	General Data Protection Regulation
GP	General Practitioner
GPSoC	General Practice System of Choice
HCP	Health Care Professional
HRA	Health Research Authority
ID	Identity
IVR	Interactive Voice Response
LTC	Long Term Conditions
NA	Not Applicable
ND	Not Documented
NHS	National Health Service
NIHR	National Institute of Health Research
ONS	Office for National Statistics
PBRN	Practice Based Research Networks
PDA	Personal Digital Assistants
PIL	Participant Information Leaflets
PPIE	Patient and Public Involvement and Engagement
QOF	Quality and Outcomes Framework

REC	Research Ethics Committee
RUG	Research User Group
SDM	Shared Decision Making
SPCSC	School of Primary, Community and Social Care
SMS	Short Message Service
SNOMED-CT	Systematized Nomenclature of Medicine Clinical Terms
TECS	Technology Enabled Care Services
UK	United Kingdom

1 INTRODUCTION

“You have your way. I have my way. As for the right way, the correct way, and the only way, it does not exist.”

— Friedrich Wilhelm Nietzsche

1.1 Overview

Choosing which data collection method to use when conducting research is a predicament faced by many researchers (Paradis, O'Brien, Nimmon, Bandiera, & Martimianakis, 2016). When investigating health, and health services, there are a number of factors which need to be considered, depending on the research question, which will help the academic team choose an appropriate method for the collection of data. The scientific rigour of the method selected is not only affected by the reliability and validity of the method (Bowling, 2014), it can also be affected by the cultural context and therefore, the perceptions and beliefs of investigators (National Science Foundation, 2002) .

1.2 Context

Reviewing the literature available on effective and fruitless, efficient and inept, and the advantages and disadvantages of existing data collection methods is helpful, but with advancements in digital approaches over recent years, combined with the recent introduction of the Data Protection Act 2018 (HM Government UK, 2018), knowledge gaps and apprehension around the use of newer (or more novel) data collection methodologies are anticipated.

The National Institute of Health Research (NIHR) Clinical Research Network (CRN), on behalf of the Department of Health and Social Care, supports and enables high-quality health and care research in England. During 2019/20, a total of 732,176 participants took

part in NIHR CRN supported clinical research studies across England. This is the highest participation number since records began (NIHR, 2021). However, despite nine out of ten patient contacts with the National Health Service (NHS) taking place in primary care settings (House of Commons, 2016), participation of patients in primary care research studies contributed only 20.7% (151,868 patients) of the total number recruited (NIHR, 2021). Primary care has a unique place in the NHS in England. With approximately 8,000 general practices in England, providing more than 340 million consultations every year, general practice has been described as the "*Jewel in the Crown*" for the NHS (NIHR, 2019). 98% of people in the UK are registered with a General Practitioner (GP). With ever increasing demands on its workforce, it is increasingly under pressure to deliver high-quality and cost-effective services which might be one of a range of reasons for the proportionately smaller number of patients recruited to research studies in this setting (Baird, Charles, Honeyman, Maguire, & Das, May 2016).

Research is central to the NHS (NHS, 2009) and there is a responsibility for the NHS to involve all NHS employees, patients and carers in decisions about their health and care. The NHS pledges to provide the information required to enable healthcare decisions and support patient choice (Department of Health & Social Care, 2015). Barriers to GPs undertaking, participating and delivering research include; a lack of research skills and research training opportunities; a lack of interest; the absence of Research and Development (R&D) departments in primary care; clinical, managerial and administrative workload and the challenges of conducting research in a '10 minute consultation'; and financing to support the research capacity (Salmon, et al., 2007). A report conducted by The Kings Fund in 2016, identified that demands on general practice now also include services previously provided in secondary care, now being provided in primary care (The Kings Fund, 2016). For research however, things have improved over the last ten years, with the inclusion of a primary care R&D spend, providing training and capacity initiatives and research support funding (Jones, 2000). There are also opportunities now, for general

practices to make better use of digital resources to participate and involve their patients in research but these are currently under-developed and under-researched (Baird, Charles, Honeyman, Maguire, & Das, May 2016). There are multiple case-finding opportunities which the primary care setting can offer for research and the use of digital resources for facilitating research in this sector, requires further exploration. In order to do so however, general practices require support to develop their digital processes and improve the digital skills of their staff, thus to alleviate apprehension around use.

1.3 Technological innovations

In order to support the delivery of health and social care across organisational boundaries, the role of Technology Enabled Care Services (TECS) are gaining increasing recognition (Chambers R. , Code of practice for technology enabled care services for Staffordshire Local Digital Roadmap, 2017). We can provide parallels in how people have converted to using technology in their everyday lives, for example in banking, shopping and communications, with how people receive the provision of health and social care (Chambers & Schmid, Making technology-enabled health care work in general practice, 2018). The use of TECS support the transformation of new models of care delivery and allow patients to meet their needs and preferences, together with the provision of efficiencies for general practice. Improving digital literacy across the health and social care landscape needs to be embedded in organisations and individuals (Royal College of Nursing, 2017).

With the emergence of the Corona Virus Disease (COVID 19) in December 2019, which was characterised as pandemic in March 2020, many changes have now occurred within the UK health system with the way in which healthcare is delivered, administered and managed. '*Remote digital health technology can foster a more holistic and ultimately effective approach to taking care of health and health issues'* and for example, telehealth, is now a necessity (Kimpen, 2020).

The inception of this thesis was commenced prior to the emergence of the pandemic. At that time, when visiting a general practice for a booked appointment, instead of patients needing to 'book in' with the receptionist, it had become commonplace for general practices to host an automated check-in screen. Some automated check-in screen systems can be enhanced from their basic functioning with additional software, to allow the collection of routine data that is saved in the electronic patient record e.g. patient smoking status, the update of patient preferences, or the delivery of patient, administrative or health messages. In a time where primary care is underfunded (NHS, 2016), automated check-in is a cost-effective process which frees up receptionist time for other more complex tasks (Williamson, 2016). Patients independently approach the check-in screen, usually located close to the entrance of a general practice, touch the screen to select successively their sex, and their day and month of birth, to let the practice know that they have arrived and are ready for their consultation. They'll then receive a confirmation of their appointment in seconds, while EMIS Web integration updates the clinical system of the patients' arrival, without staff having to take any action, see Appendix 1 (Egton, 2021). Whilst this automated process provides an efficient solution to the completion of a practice administrative function, it may also be possible to re-purpose its function, to be used as an efficient research recruitment and data collection tool. An automated check-in screen which displays additional health related questions could also be one way of providing patients with the ability to take control of their choices and how their personal data are managed.

1.4 Thesis aim

The aim of this thesis is to investigate the utility of an automated check-in screen to collect brief research data from patients, whilst they are confirming their attendance for a booked appointment within primary care, specifically general practice settings. This is the first time that this has been investigated and therefore will provide new evidence for the use and effectiveness of automated check-in software used to collect data for research purposes.

The thesis begins with a description of the cross-sectional study that was designed to collect research data from participants using an automated check-in screen. The research question, aim and objectives are first described. This is followed, by a description of the strengths and weaknesses associated with widely used data collection methodologies, currently employed for use in primary care research, and an introduction to the broad landscape of automated technologies. The systematic literature search, of existing published information on the use of automated data collection methodologies used within primary care to collect research data, is then described. This is followed by a detailed description of the development of the cross-sectional study assessing both the research question and the use of an automated check-in screen to collect brief patient research data within the general practice setting. Empirical data resulting from the described cross-sectional study is then analysed, interpreted and discussed in context with existing data and data collection methodologies. Findings are then used to inform future recommendations and additional research requirements around the optimal methods for the collection of research data from patients, to provide a reduction in the responsibilities required of the healthcare team when conducting research, within primary care settings.

2 RESEARCH QUESTION, AIM AND OBJECTIVES

“Research is creating new knowledge.”

— Neil Armstrong

In this chapter the research question, aim and objectives for the conduct of the pilot-feasibility descriptive cross-sectional study, are described.

2.1 Aim

The aim of this research study is to investigate the utility of check-in screens as a research tool and to examine patient acceptability in providing brief research information, whilst completing an automated check-in screen, prior to an unsolicited general practice consultation. To do this, patients were asked a brief question on their level of bodily pain at check-in and a question on whether they would be happy to be contacted, by their practice, about future research studies of relevance to them.

2.2 Objectives

By piloting the use of the automated check-in screens to collect brief research data, the aim of this thesis will be achieved through the following specific objectives:

i. To estimate the number of patients reporting a degree of pain and which severities of pain, using a 1-6 point scale.
ii. To estimate the number of patients that would be happy to be contacted about future research studies relevant to them.
iii. To examine completion rates of two research questions on the automated check-in screen.

iv. To explore demographic variations such as age and gender[1], in completion responses.

v. To estimate research question completion rate feasibility, for future use of automated check-in screens in the collection of research data.

vi. To explore question completion rates depending on the time difference between; check-in completion and booked appointment time.

vii. To assess the impact of check-in completion on general practice operationalisation using diary data completion by practice administrators and to describe the quantity and detail of any participant queries.

The answers to these objectives will then provide feasibility information to inform the future use of this innovative data collection methodology, for the collection of brief patient reported research data.

2.3 Research question subject areas

In order to test the approach, two different question domains were selected to assess willingness to participate with different types of questions. The subject and format of research questions can impact on completion rates (Newington & Metcalfe, 2014). For this reason, one 'clinical' question asking about the level of bodily pain patients experienced during the past 4 weeks and a 'non-clinical' question asking patients about whether patients would be happy to be contacted, by their practice, about future research studies of relevance to them, were chosen.

2.4 Research question description

The completion rate of both a 'bodily pain' focussed research question, and a 'contact about research' question, will be explored.

[1] Gender, as recorded by the general practice electronic medical record system.

2.4.1 ‘Bodily pain’ research question

The research programme delivered by the School of Medicine at Keele University delivers high-quality multidisciplinary research, designed to improve the content, delivery and configuration of primary care for the benefit of patients with musculoskeletal conditions, mental health problems, cardiovascular disease and other long-term conditions (Keele University, 2021). Within the research themes of: Musculoskeletal Pain and Stratified care; Osteoarthritis and Osteoporosis; and Inflammatory Conditions, our research aims to improve the management of pain.

The first research question to appear on the automated check-in screen, after patient completion of demographic details (as standard) is:

“How much bodily pain have you had during the past 4 weeks?”

With options for completion of;

“None”, “Very mild”, “Mild”, “Moderate”, “Severe”, “Very severe”

or

“Skip”

Findings from this research question will provide a contribution of new information to the research themes at Keele University that are investigating pain, and more widely to the research community, our understanding of pain, and to GPs treating their patients presenting with bodily pain.

2.4.2 ‘Contact about research’ question

The invitation to participate in healthcare research and the percentage conversion rate into participants recruited is variable (Walters, et al., 2017). A question for patients to complete at automated check-in, with regards to whether they would be happy to be contacted, by the practice about future research studies, would provide the patient with some control over

how their data is being used by the general practice. It also provides us with information about patient preferences, which could contribute to a wider campaign on encouraging people to participate in research (https://bepartofresearch.nihr.ac.uk/). It is also a 'non-clinical' question and thus, an impersonal question than the previous, 'clinical' bodily pain question and as such, we may see a different response.

The second research question to appear on the check-in screen, is:

"Would you be happy for your practice to contact you about any future research studies which are relevant to your health, to improve care for patients in the NHS?"

With options for completion of;

"Yes, I'd be happy for you to contact me about research of relevance to me",

"No, thank you"

or

"Skip"

Findings from this research question will restore the equilibrium between the processing of patient data for research, within a digitalised and globalised world and protect the rights of patients at participating general practices, providing them with more choices over how their personal data are used (Chassang, 2017).

2.5 Summary

More detail on the research questions is provided in Chapter 5, section 5.2 Data Collection. The following chapter will describe the range of data collection methodologies commonly employed for use in the collection of research data, for clinical research within the healthcare sector.

3 BACKGROUND

“Data! Data! Data! I can’t make bricks without clay!”

— Sir Arthur Conan Doyle

This chapter introduces data collection methods routinely employed when conducting research within the healthcare sector, along with a discussion on the strengths and limitations associated with each methodology. Alternative data collection methodologies are then explored, and electronic clinical record management systems are described. As adherence to legislation for the collection of data is a statutory requirement, an explanation of the governance surrounding the use of personal data, is also provided.

The method of data collection used for research must be selected appropriately to effectively test the hypothesis, evaluate outcomes and answer the research question. Structured research data collection on relatively large, representative populations will typically be carried out using quantitative research methods. However, if the research topic is exploratory and or complex, then a qualitative research method may be more appropriate, usually utilising a smaller sample size (Bowling, 2014) but investigating the topic in more depth. For the purposes of this thesis, which investigates automated data collection from patients from general practice settings within primary care, quantitative methods of research data collection will be the primary focus.

3.1 Reliability and validity

Reliability and validity are concepts used to evaluate the quality of research (Sim & Wright, 2000). For the purpose of this thesis, they can be used to assess how well the automated check-in screen data collection methodology collects brief research data from patients consulting in general practice. “*Reliability refers to the reproducibility and consistency of an*

instrument." "Validity is an assessment of whether an instrument measures what it aims to measure." (Bowling, 2014)

Reliability in the context of this thesis is essentially the degree to which automated check-in screens can collect stable and consistent data. Validity refers to how well the displayed research questions collect data, that they are purported to collect. Whilst formally testing the validity of the data to be collected is not an objective of this thesis, it is recognised that the less variation an instrument produces in repeated answers to a question, the higher its reliability (Bannigan & Watson, 2009).

3.2 Data collection methods for quantitative research

Quantitative data collection methods derive data in a way that is independent of the expectations of the observer and are used to quantify a problem by way of generating numerical data or data that can be transformed into usable statistics (Botti & Endacott, 2008). Data collection for quantitative health research can involve; the collection of retrospectively recorded data (e.g. medical records), surveys, and systematic observations (The Open University, 2017) (Jason & Glenwick, 2016). A combination of these methods can also be used to ensure that the data collection is suitably structured and provides the required depth of data required to answer the research question.

Broken down into more detail, quantitative data collection methods can include;

- **Retrospective data collection**

  Data collected from existing records and recorded using a case report form (Jansen, et al., 2005) or used directly from their source e.g. Clinical Practice Research Datalink (CPRD) (Department of Health and Social Care, 2020).

- **Survey data collection**
  - Questionnaires;
    - online questionnaires (O)

An online questionnaire is one which the target audience can complete using the internet.

- paper questionnaires (P)

  A paper questionnaire is one which is administered on paper and requires manual completion by the target audience using a writing implement (e.g. ink pen, pencil).

- mobile phone questionnaires (M)

  A mobile phone questionnaire is one by which the target audience receive messages and complete by responding via their personal mobile phone device.

- anonymous kiosk questionnaires (K)

  A stand-alone device which allows the target audience to voluntarily provide anonymous feedback is described as, a kiosk.

- longitudinal questionnaires (L);

  A longitudinal questionnaire can vary in its administration however is a research design that involves repeated observations of the same variables.

➢ Interviews;

- face-to-face interviews (F)

  A face-to-face interview involves an interviewer directly communicating with the respondent in accordance with the prepared questionnaire, to collect quantitative data.

- telephone interviews (T);

  A telephone interview involves an interviewer communicating with the respondent over the telephone, in accordance with the prepared questionnaire, to collect quantitative data.

- **Systematic observations**

  Using techniques like counting, thus quantifying the behaviours of interest.

Whilst each method of data collection has its advantages and disadvantages, each method also has implications for bias (Bowling, 2014). Bias is any trend or deviation from the truth in sampling, data collection, data analysis, interpretation and publication which can cause false conclusions (Fletcher & Fletcher, 2005). Use of inappropriate techniques or faulty design in methods or procedures, can lead to a difference between the observed outcome and the true outcome. O'Leary (2004) further remarks, that it is worth remembering that one method of data collection is not inherently better than another. Each data collection method needs to be considered in light of the research question, pragmatic considerations and the research goals, alongside the inherent pros and cons for each method for the context of the target participant population. The specific variables; population, setting and data required, which define a research question must be considered in line with; timeliness, accessibility and funding available to collect the required data. Table 3.1 summarises the advantages and disadvantages of routinely employed quantitative data collection methods (O'Leary, 2004), (Rea & Parker, 2014).

Table 3.1 Summary of the advantages and the disadvantages of data collection methodologies

	General Advantages	General Disadvantages
Retrospective	• Lower cost • Unobtrusive • Large samples • Useful for trend analysis	• Accessibility • Historic • Difficult to assess validity • May not be data on knowledge, attitudes or opinions • Unrecorded data
Survey	• Relative low cost (O,P,M,K) • Convenient (O,P,M,K) • Large geographical area sampling (O,P,M,L,T) • Rapid data collection (O,M,K,T) • Can target specific populations (O,P,M,K,L,F,T) • Can cover large numbers of respondents (O,P,M,K,L) • Specific questions can be asked (O,P,M,K,L,F,T) • No interviewer bias (O,P,M,K,L) • Effective for sensitive subjects (O,P,M,L) • Responses can be controlled (O,P,M,K,L)	• Relatively costly (L,F,T) • Time consuming (P,L,F,T) • Small geographical area sampling (K,F) • Relatively low response rates (O,P,L,F,T) • Gauging salience and context of responses (O,P,M,K,L) • Restricts questionnaire length (M,K,T) • Missing data (P,M,L) • No opportunity to clarify or explore in-depth issues (O,P,M,K,L) • Biases:

	General Advantages	General Disadvantages
	• Anonymity (P,K) • Complexity (O,P,L,F) • Visual aids can be used (O,P,K,L,F) • Ease of follow-up (O,L) • In-depth data collection (O,P,L,F,T) • Opportunities to clarify responses (L,F,T) • Missing data less common (O,K,F,T)	-recall/memory (O,P,L,F,T) -non-response bias (O,P,L,M,F,T) -sampling bias (O,P,M,L,F,T) -interviewer bias (F,T) • Limited quantitative data (M,K,F,T)
Systematic observations	• Effective for sensitive subjects • Can target specific populations • Complexity • In-depth data collection	• Relatively costly • Time consuming • Small geographical area sampling • Interviewer bias • Limited quantitative data

Methodology; online questionnaires (O), paper questionnaires (P), mobile phone questionnaires (M), anonymous kiosk questionnaires (K), longitudinal questionnaires (L), face-to-face interviews (F), telephone interviews (T).

3.2.1 Retrospective data collection

NHS England has committed to making patients' health records *'largely paperless'* by 2020 (NHS, 2014). At present, patients may have several different paper and electronic medical records stored in various healthcare settings. NHS England intends to connect these up across primary, community, secondary and social care settings, which would allow people to monitor their own health, improve patient safety and outcomes, and would also aid the collection of data for research (Parliamentary Office of Science & Technology, 2016). It has been recognised that the adoption and comprehensive use of integrated electronic health records will provide multiple benefits (Rumball-Smith, Ross, & Bates, 2019). There are however various forms of 'integrated care record' software currently available and as such, one single joined up system is not used by all providers.

The quality of retrospective data collection can be enhanced with the use of a data collection protocol and a well-designed case report form to ensure consistency amongst data collectors (Jansen, et al., 2005). However, notes made in the patient record are intended for patient care, as opposed to research purposes. With some information not always well documented in the patient records, retrospective data collection can result in missing data or interpretation issues especially if coded data is relied upon. The use of data collection guidelines can prevent some misinterpretation in outcome definition and further, caution is required when assessing accuracy and completeness of the data available (Bowling, 2014).

General advantages of collecting retrospectively recorded data are that large samples of data can be collected relatively unobtrusively and at a low cost, using a standardised data collection form to ensure consistency and to provide representative trend analyses. The disadvantages of this method include; the accessibility of the data – where is the data now stored? Is access readily available? Will access come at a financial cost? Historical recording – making it difficult to assess validity of what has been recorded; and missing

data will be difficult to report – if the data required for capture is not available in the record, it cannot retrospectively be gained.

3.2.2 Survey data collection

Self-completion surveys have been widely used for obtaining data. If the sample is representative, findings should reflect the population of interest (Aldridge & Levine, 2001) if an appropriate sampling frame is used. They are used for research purposes, ranging from simple market research, to national population-based censuses. Surveys can be conducted in a variety of formats to include; telephone, self-completion and individual face-to-face interviews.

3.2.2.1 Questionnaires

The questionnaire was invented by the Statistical Society of London in 1838 (Royal Statistical Society, 2019) with self-administered survey questionnaires remaining an important data collection methodology used in clinical practice, public health research and epidemiology (Belisario, et al., 2015). They are used to quantify attitudes, opinions, behaviours, and other defined variables as a way of generalising results to represent a larger sample population.

The traditional paper questionnaire, containing a list of questions for completion by the subject, is relatively straightforward to collect data with, however it may be difficult to elicit reliable data from respondents (Smith, Morrow, & Ross, 2015) (Gillham, 2007). This is because the questions and the possible answers are determined in advance, the element of discovery therefore is much reduced. Obtaining worthwhile and generalisable data from questionnaires needs careful planning and design (Boynton & Greenhalgh, 2004). There are many factors to consider in the production of an effective questionnaire. The information to be collected must firstly be considered. Validated questionnaires are precision

measurement instruments. A validated tool with high precision, is one whereby the spread of readings is small and results are consistent when measurements are repeated (Fletcher & Fletcher, 2005). If it is that a questionnaire is appropriate, then the use of validated tools will ensure that the data collected is valid and reliable (Juniper, 2009). Questionnaire items can be presented in various formats, and how questions are presented can potentially affect response rates. Use of a mixture of open and closed questions, Likert scales (a closed scale that provides a series of answers, from one extreme to another) and good completion instructions, can improve response rates (Boynton & Greenhalgh, 2004). Modes of administration for invitation and subsequent response can also affect the type of responses obtained (Mallen, Dunn, Thomas, & Peat, 2008).

Consideration of the overall design and format of a questionnaire has to be made in order to maximise the accuracy of the data collected. Each question needs careful construction to avoid ambiguity (by avoiding double barrelled questions (where you ask two questions but only allow for one response e.g. Do you like x and y?), technical jargon and vague or inaccurate words (which may have variable interpretations e.g. 'nice')). This is best prevented by ensuring that the questionnaire is 'tested' first with a representative patient user group. The approach taken to involving members of the public in the design of the survey used for the purpose of this thesis is described in more detail in Chapter 5.

The accuracy of data obtained from questionnaires can also be dependent on the order of the questions and with closed questions involving multiple-choice answers, the order of responses. If participants are given a set of answers for a question to choose from, then too few categories may cause participants to be forced into making a decision that they may not want to. Too many categories may lead to end aversion (not wanting to give the best or worst mark because it is at the end of the scale) and also response fatigue (Choi & Pak, 2005).

The administration of self-completion questionnaires can be provided via a number of mediums to include; online, paper, text message, and kiosks. These methods all provide advantages in being relatively low in cost to administer, convenient, can target specific populations and removes any interviewer bias. The disadvantages that all of these methods possess though; is the inability to determine the context of responses and the salience with which they were completed. Despite being able to remove interviewer bias through self-completion techniques, these methods neither provide any opportunity to clarify or explore responses. Depending on the management of their administration, responses from online, paper and kiosk questionnaires can also be completed anonymously with very little demographic information required or obtained from the respondents. Kiosks in particular, are now commonly used in the leisure and retail industries. They are operated by the user in an anonymous format to either, provide information or to gain customer service feedback. Another significant feature of many kiosks, is that they operate independently from any other system.

3.2.2.2 Interviews

Whilst costly, time consuming and often used for relatively smaller sample sizes, interviews (face-to-face, online or administered via telephone) to collect quantitative data have a number of advantages. Missing data is at a minimum as interviewers can probe fully for responses, inconsistencies or any ambiguity can be checked, complexity in the questioning can be incorporated, there are reduced literacy requirements of the sample and response rates are generally higher than those obtained by self-completed questionnaires (Bowling, 2014).

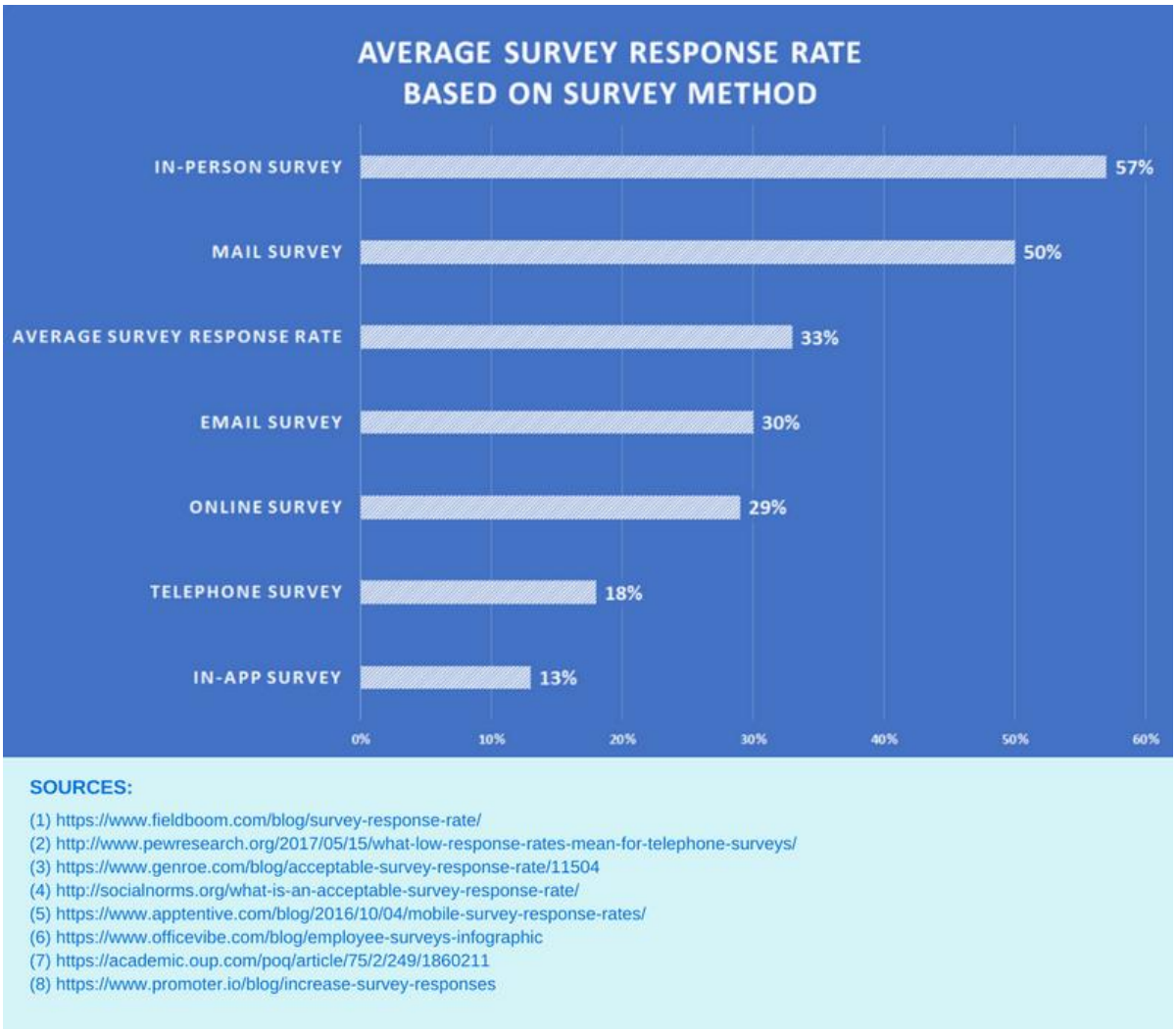
An effective interview survey to collect quantitative data, is to some extent dependent on the skills and abilities of the interviewer and so interviewer training in the questionnaire delivery is key for this approach. Interviewing has often been considered as being more subjective, or prone to individual interpretation, however they remain very useful in

gathering detailed quantitative data. The quantitative data collection obtained from an interview is concise and is collected without the additional opinionated detail provided with the reasons for response, in line with the structure of the survey. This style of interview offers the ability to provide a convenient summary evaluation (Nardi, 2018).

3.2.2.3 Response rates

Data collection methods are most effective when triangulated with other methods, for example when self-reported data is compared to that of retrospective review of medical record data. A disadvantage of one data collection method can be the advantage of another (Madziwa, 2014). For example, if in the return of a self-completed questionnaire there are missing data, then an interview may be used to collect responses to missing data and so using multiple data collection methods with synergistic strengths can improve data quality. Lindemann describes the average response rate from self-completion surveys as 33% (Lindemann, 2019). Whilst there have been many studies conducted on the response rates achieved using a variety of different survey methodologies, authors do not allude to an expected response rate, instead they provide guidance for how response rates can be optimised and then what can be expected if their advice is followed, *"…a high response rate is achievable"* (Opie & Brown, 2009). Whilst there is no agreed-upon minimum acceptable response rate, survey subject, delivery method, length, target audience and provision of incentives are some examples of parameters that can influence response rates. Figure 3.1 provides us with an infographic developed by Lindemann, which combines response rates from a variety of recent studies to display how variable response rates can be. This infographic however implies that those methods with minimal human interaction, using technology enabled methods of data collection, have a lower response rate than others. Automated data collection methodologies will be explored further, in section 3.2.4.

Figure 3.1 What's the average survey response rate? [2019] (Lindemann, 2019).



3.2.3 Systematic observations

Assessment strategies used to document the behaviour, activities, knowledge or skills of a sample, are referred to as systematic observations. These ideally, should again be part of a triangulated research methodology if possible or needed, in order that observed events can be verified by independent and alternative methods (Bowling, 2014). Systematic observations are effective for targeting specific populations and exploring sensitive subjects. Detailed data collection can be obtained using this methodology; however, it can be very time consuming, costly and therefore only effective for small samples or sub-samples.

3.2.4 Automated data collection

Whilst the decision to participate in clinical research is multifaceted; infrastructure, the nature of the research, recruiter characteristics, and participant characteristics can all influence the success of recruitment (Newington & Metcalfe, 2014). Automated data collection can quickly and efficiently process large amounts of information with minimal human interaction and potentially at lower cost. A biometric system which uses information based on physiological characteristics of a person to identify eligibility for research automatically is advantageous as it removes the recruiter to participant relationship dimension, however the research also needs to be accessible, to encourage participation (Harris, et al., 2018). In order to ensure accessibility, consideration needs to be applied to; language, style of writing, font, the provision of clear and cohesive instructions to ensure simplicity and availability of the data collection medium.

Technology-based data collection methods are now widely available and include web-based programs, mobile applications, Short Message Service (SMS) and wearable devices (Eldridge, et al., 2018). It has been recognised that technology-based methods improve accuracy and reduce costs of data processing. They can also maximise scalability and speed up data collection (Belisario, et al., 2015), as delivery and receipt of response is carried out electronically, again reducing costs.

Flowcharts are used to analyse, design, document and manage a process. They provide a diagrammatic visualisation of all possible eventualities resulting from a process and allow the reader to logically follow a process from beginning to end. Flowcharting the specifications for electronic data capture is essential to ensure minimal missing data. Routing (also known as skip-logic or branching) allows a participant to be directed through a survey based on the answers that they give. If the participant provides a particular answer, they can then be directed to the next relevant question for them. Routing can be used to make long surveys shorter by allowing participants to automatically skip irrelevant

questions. Routing can also be used to make basic surveys more investigative by branching off into areas tailored to certain groups of participants. The automatic identification and data capture market is expected to grow at the highest rate between 2018 and 2023 (Wood, 2018).

3.2.4.1 Mobile technology

In the UK, 96% of all adults now own a mobile phone and 80% of adults own a smart phone (Ofcom, 2019). This presents an opportunity for researchers to communicate with participants in order to gain self-reported data. There are two main ways that mobile phones can support self-report data collection. The first is via Short Message Service (SMS) and the second, for those owning a smart mobile or smartphone, is via applications (apps) – which have been derived from online access to data collection portals and surveys. There is little evidence available in the literature on the optimal way to use mobile technologies for the collection of self-report research data (Walsh & Brinker, 2019), however in the use of mobile technologies for research, consent to participation will already have taken place before any investigation into the optimal way to use mobile technologies can occur.

3.2.4.2 Patient portals

Web and app-based portals provide access to electronic health records, self-help and self-management resources for patients (NHS Digital, 2016). The number of online patient portals available for use is increasing and whilst interaction with patient portals has been extensively studied, little is known about the influence they may have on patient decision making (Fraccaro, et al., 2017). It is thought that more research is required on identifying specific populations and the contextual considerations which would provide an increase in adoption of use (Irizarry, DeVito Dabbs, & Curran, 2015). Poor quality health information and ‘fake news’ which can also be found online though, requires a critical appraisal of any sourced information. Patient portals play a valuable role in patient engagement and in the

provision of access to information for patients, their use in the collection of data is limited to only that of user characteristics (Alturkistani, et al., 2020).

3.2.4.3 Technology Enabled Care Services

Technology Enabled Care Services (TECS), include telehealth, telecare, telemedicine, telecoaching and self-care apps. These aim to empower patients in managing their own healthcare and encourages the innovative use of technology to improve healthcare outcomes for those patients managing long term conditions (LTCs) (NHS England, 2019). Telehealth systems for example, support those with LTCs to self-manage their conditions resulting in; patients remaining more independent; a reduction in hospital admissions; earlier hospital discharges; and a reduction in dependency on primary care services. These systems provide automatic coaching and mentoring to the patient through a series of questions and answers which are then processed by software algorithms (Chambers, Schmid, & Birch-Jones, Digital Healthcare: The Essential Guide, 2016). Telehealth plays an important role in maintaining a continuity of care with patients and in the collection of patient clinical data. It is also possible to use telehealth data to support aspects of clinical research, such as; patient information, consent, data collection for remote study designs and treatment delivery. Telehealth is an integral part of clinical care and research to augment in-person interactions (Kleykamp, Guille, Barth, & McClure, 2020)

3.2.4.4 Personal Digital Assistant

Advances in handheld computer technology are making data collection at the point of contact with patients faster, easier and more accurate (Guadagno, et al., 2004). This is still the case, however, in recent years the use of voice-controlled personal assistants, Personal Digital Assistants (PDAs) (Srinivasan & Madheswari, 2018) have become much more common-place. PDAs are widely described in the literature for use by clinicians and researchers, to increase the performance of data collectors using these devices. They allow

real time data collection at the point of care and in comparison with paper data collection methods, the use of PDAs showed improvements in the storage, management and collection of data (Naqvi, Mehta, & Sharma, 2018). The maintenance of data confidentiality and security are measures which need to be taken and they do not allow for patient use in an automated context.

Complex algorithms for data collection which can be difficult to follow on paper are simplified with data collection via PDAs. Routing and question skipping are relatively easy to program into PDA systems. Skip patterns which appear somewhat overwhelming on paper are virtually transparent to PDA users (Pace & Staton, 2005).

3.2.4.5 Limitations of automated data collection methodologies

The use of automated data collection methodologies can present restrictions for both the researcher and the subject providing data. For the researcher, the inability to customise data collection and automatic reports has provided frustrations (Eldridge, et al., 2018), and there is concern around the privacy of patient data (Chambers & Beaney, The potential of placing a digital assistant in patients' homes, 2020) . Other challenges for the introduction of newer technologies in general can include; lack of timely evaluations; and overestimating expectations as a result of the rapid introduction of new technologies (Meinert, et al., 2018). For the subjects, the usability of the data collection medium may introduce restrictions based on age, literacy, vulnerability, language and acceptability. A study conducted on older adults' perceptions of technology however found that participants were eager to adopt new technology but just expressed apprehension about a lack of clarity with instructions and support (Vaportzis, Clausen, & Gow, 2017). In addition, digital health-care technology benefits are not equitably distributed. Improvements in technologies can cause disparities in health due to digital exclusion and the requirement to have access to: a computer, the internet, WI-FI, a smart phone, applications etc. This digital divide has also been heightened more recently since the advent of COVID-19 (Watts, 2020). Conversely, digital solutions

can also help some of the underserved populations access healthcare. Easy to use and intuitive automated methodologies are therefore preferable to ensure maximum participation. The automated check-in screens meet this criteria, as they are a low-tech or unsophisticated solution, which require little usage instruction and do not require participants to: have an enabled electronic device, have access to the internet, or download an application. Thus, making participation in research accessible.

3.3 Primary Care Clinical Record Management Systems

The electronic Clinical Record Management system which each general practice uses is a system selected to best suit their needs from a range of four principal system suppliers selected from the General Practice System of Choice (GPSoC) framework (NHS Digital, 2019). The GPSoC are; Egton Medical Information Systems (EMIS Web) (EMIS Health, 2020); The Phoenix Partnership Ltd. Secondary Care. Mental Health. Social Care. (TPP SystmOne) (TPP, 2020); In Practice Systems Ltd (InPS Vision) (Vision Health, 2020); and Microtest Evolution (Microtest Health, 2020). These systems are used by 56%, 36%, 7% and 1%, of general practices respectively within England (NHS Digital, 2018). The basic system is purchased for the practice by the NHS Clinical Commissioning Group (CCG), who places the order for the GPSoC on behalf of the general practice.

These GPSoC are now designed to include optional extra features for general practices to invest in as they wish; patients can be provided with information, provide feedback for service evaluation and book future appointments using the interoperability functions of these systems (EMIS health, 2019). All of the approved systems integrate with automated check-in screens, which most general practices encourage patients to use for notification of their arrival for an appointment (by selecting the day of the month they were born, the month they were born and then the first letter of their surname (as standard)). An automated touch screen operated by the patient can update the GPSoC with the patient's arrival for

their appointment and the patient receives confirmation of their appointment in seconds, without administrative staff having to take any action. This potentially frees up reception staff to conduct more complex tasks. In addition, the EMIS Web GPSoC has an associated Questionnaire Module, which can be used to gain additional responses from patients in order to improve services or collect NHS Quality and Outcomes Framework (QOF) data, the system for performance management and payment of NHS general practitioners (GPs).

EMIS Web is the clinical system of choice used by 67% of practices across the NIHR Clinical Research Network: West Midlands (CRN WM) footprint (Kontopantelis, et al., 2018) and the customisable options it offers provides an opportunity to pilot this GPSoC in the collection of additional, brief research data from consulting patients. Regionally this equates to 652 general practices with a population of approximately 4,890,000 patients who could be providing brief research data in the CRN WM alone.

3.4 General Data Protection Regulation

When identifying participants for research there are a number of key considerations, including confidentiality and information governance (HRA, 2018). General Data Protection Regulation (GDPR) strengthens the rights of patients over the use of their personal data. Individuals now have greater rights over what data about them is being processed by whom, why, where and how. Data controllers are now more accountable for what they do with and how they protect personal data. For any breaches in the new regulations the penalties are also much higher. The Health Research Authority (HRA) however, have not added to the existing effective safeguards for health and social care research, as the new regulation is not very different from the previous Act in terms of research data collection. The GDPR restores the equilibrium between the processing of patient data for research, within a digitalised and globalised world and protects patients' rights, providing them with more choices over how their personal data is used (Chassang, 2017). Whilst GDPR is a piece of

European Union (EU) legislation, following Brexit on 1st January 2021, it has since been incorporated into United Kingdom (UK) law.

Whilst GDPR brings rise to legislative adherence, since its release in April 2018, there has been a growing number of concerns around the development of the General Election 2019 Trade Policies. In particular, the sharing of anonymised data sets with international pharmaceutical companies, for the purposes of research. Where these concerns exist, this could lead to a barrier in patient participation with research. It is important therefore that participant data sharing attitudes and preferences are considered (Howe, Giles, Newbury-Birch, & McColl, 2018).

3.5 An international perspective

It is internationally recognised that care coordination represents a major challenge for primary healthcare systems, especially with the increase in the elderly population and the increase emphasis on long term chronic disease management (Khoo, Lim, & Vrijhoef, 2014). Alongside technological advances, efficiency initiatives for data collection and the management of data have been implemented. Examples of these initiatives can be found internationally, which have been developed around the infrastructure available and the population they are to serve:

- Email consultation is mandatory for general practice service provision in Denmark, with the email consultation being directly incorporated into the patient's electronic record (Chambers, Schmid, & Birch-Jones, Digital Healthcare: The Essential Guide, 2016).
- There is a single electronic healthcare record in Singapore, managed by the Singapore Government. This provides accessibility and acceptability of a single electronic automated system for patients to use to administer their healthcare needs, e.g. book appointments, check-in etc.

- Automated health kiosks are accepted, for the provision of healthcare information through the use of a touchscreen computer, among African Americans in hard to reach community settings such as churches and community centres (Abraham, Patel, & Feathers, 2018).

With increasingly limited resources in healthcare services, a rise in demand for efficiency and effectiveness puts healthcare systems worldwide under pressure to continuously deliver high quality care. Global health research can transform clinical practice, however data accuracy still remains a hurdle in global research (Quinsey, et al., 2018). Research bodies such as the Institute for Healthcare Improvement (IHI) in the US, the UK's Institute for Innovation and Improvement, and the Australian Institute for Health and Welfare, were established to investigate the mechanisms behind effective and sustainable improvement initiatives (Curcin, Woodcock, Poots, Majeed, & Bell, 2014). Digital improvement initiatives represent an important part of achieving change in a healthcare system, however for participation in research using automated data collection processes, every worldwide population faces their own set of challenges to include; legislation, digital infrastructure, capabilities and capacity; adoption and acceptance within cultures.

3.6 Summary

In 2006, de Lusignan and van Weel identified that whilst routinely collected primary care data are aggregated for use in audit, quality improvement, health service planning, epidemiological study and research, there are gaps in the literature about how to find relevant data, select appropriate research methods and ensure that the correct inferences are drawn.

Data are used to support improvement in healthcare (Shah, 2019) and it is known that continuous data collection and analysis are essential to achieving healthcare

improvements. The collection of data though can be costly and time consuming, therefore inexpensive and rapid tools are required to support this task (Curcin, Woodcock, Poots, Majeed, & Bell, 2014). Automated modalities for the collection of data have been identified as feasible and facilitating sustainability of data collection within healthcare systems (Owen-Smith, et al., 2018). The automated modalities provide the required convenience needed for researchers and for patients to participate.

The burdensomeness of a data collection methodology is inversely related to participant response rates. Patients may want to help with research but are deterred if the research imposes too much or is multi-layered. For example, complete a survey, put it in an envelope and then post it. Each activity a separate barrier which impose on busy lives. Automated modalities utilised at the point of care, additionally provide real time data collection reducing recall bias, which is sometimes an issue with other methodologies of survey administration. For most people, contact with health services is through their GP and primary care, so it's here that there is the greatest potential for widening digital inclusion and rapidly collecting data from a generalisable sample, representative of primary care.

The following chapter will describe the systematic literature search and narrative review, carried out to explore and describe the existing information available on the use of automated data collection methodologies in primary care settings, to collect research data.

4 LITERATURE REVIEW

“If a word means everything then it means nothing.”

— Professor Richard Lilford

The literature currently available on the use of more traditionally and routinely employed data collection methodologies e.g. paper-based questionnaires and face to face interviews, is saturated enough to provide a sufficient, informative overview of their applicability. This chapter will review the literature specifically relating to patient independent use of data collection devices available in primary care settings, for the collection of research data.

4.1 Background

Automated data collection methods have the potential to quickly and efficiently process large amounts of information with minimal human interaction. Dalto [1997] identifies the benefits attributed to automated data collection in healthcare, as those associated with improvements in accuracy, completeness and time savings (Dalto, Johnson, Gardner, Spuhler, & Egbert, 1997). These same benefits are also apparent today. This chapter will summarise the available evidence around patient autonomous use of automated data collection methodologies, within primary care settings.

In order to identify and summarise the available and published literature exploring the autonomous patient use of data collection methodologies used within primary care health settings for the purposes of research, a systematic literature search and narrative review, is presented.

4.2 Aims & Objectives

This systematic literature search aims to identify articles using data collection methodologies that patients use and interact with independently, negating the need for recruiter and participant interaction.

The aims described above will be achieved through the following objectives;

i. The development of an appropriate search strategy.
ii. An online search of bibliographical databases to identify relevant articles reporting on autonomous patient use of data collection methodologies in primary care health settings.
iii. Systematic assessment of each article identified through title, abstract and full text screening.
iv. A quality assessment of identified articles.
v. Extraction of data and summary of content from selected relevant articles.
vi. Narrative summary of findings

4.3 Methods

In this section the methods used to identify relevant articles, which describe patient use of automated data collection methodologies within primary care health settings for research, is described.

4.3.1 Search strategy

By searching a list of terms, relevant articles can be found within electronic bibliographic databases. The descriptive terms reflecting the aim of the literature search, in conjunction with synonyms of these descriptors and other commonly used alternative descriptors were selected, as search terms. The search strategy was appraised by systematic review experts, to ensure a comprehensive literature search.

The following search domains were first identified;

- Primary care
- Data collection
- Automated devices
- Research

Then additional synonyms and commonly used alternative descriptors were identified. These are summarised in Table 4.1.

Table 4.1 Systematic literature search concepts

Primary Care	Data collection	Automated devices	Research
primary care	data collection	automated devices	research
first-contact	data capture	patient portals	
point-of-contact		TECS	
point-of-care		technology enabled	
general practice		kiosks	
family medicine		digital	
family practice			

The search strategy was formed by combining all terms within a concept with the OR operator, and combining the concepts together using the AND operator. The broadest terms for the key concepts were selected, combined with the use of truncation to ensure a comprehensive search. The full search strategy was as follows;

(“primary care” OR “first-contact” OR “point-of-contact” OR “point-of-care” OR “general practi*” OR “family medicine” OR “family practi*”) AND (“data collect*” OR “data capture”) AND (“automat*” OR “patient portal*” OR “TECS” or “technology enable*” OR “kiosk*” OR “digital*”) AND research

4.3.2 Data sources

The following bibliographical databases were searched from inception, to 13th December 2018, to identify relevant articles;

- Web of Science (1950 – present)

This platform provides a unique way of searching, to include the ability to perform an 'All Databases' search on the content of multiple searchable products.

[https://wok.mimas.ac.uk/]

- EBSCO – Medline (1946 – present)

MEDLINE is a database of articles from a wide range of academic journals that cover medicine, nursing, dentistry, veterinary science and healthcare as well as pure science fields including biology and biochemistry.

[https://www.ebsco.com/products/research-databases/medline]

- EBSCO – AMED (1985 – present)

AMED is a healthcare database produced by the Health Care Information Service of the British Library. It covers subject areas allied to medical professions including physiotherapy, occupational therapy, podiatry, rehabilitation medicine, palliative care and complementary medicine. The database indexes relevant articles from more than 600 journals, mainly from Europe many of which are often not indexed by other sources.

[https://www.ovid.com/product-details.12.html]

- EBSCO – CINAHL (1981 – present)

CINAHL is a research database providing details of articles from journals relevant to nursing, allied health, healthcare and biomedicine.

[http://www.ebscohost.com/academic/cinahl-plus-with-full-text]

4.3.3 Inclusion and exclusion criteria

The following inclusion and exclusion criteria were applied;

Inclusion criteria

- Research conducted in primary care health settings.
- Research detailing data collection methodologies designed for use by the patient, as opposed to collection by a Health Care Professional (HCP) or researcher.
- Research including human adults aged 18 years or older.
- Studies published in the English language.

Exclusion criteria

- Studies including data collection methodologies employed for paediatric populations.
- Articles not in English.

4.3.4 Finding and excluding articles

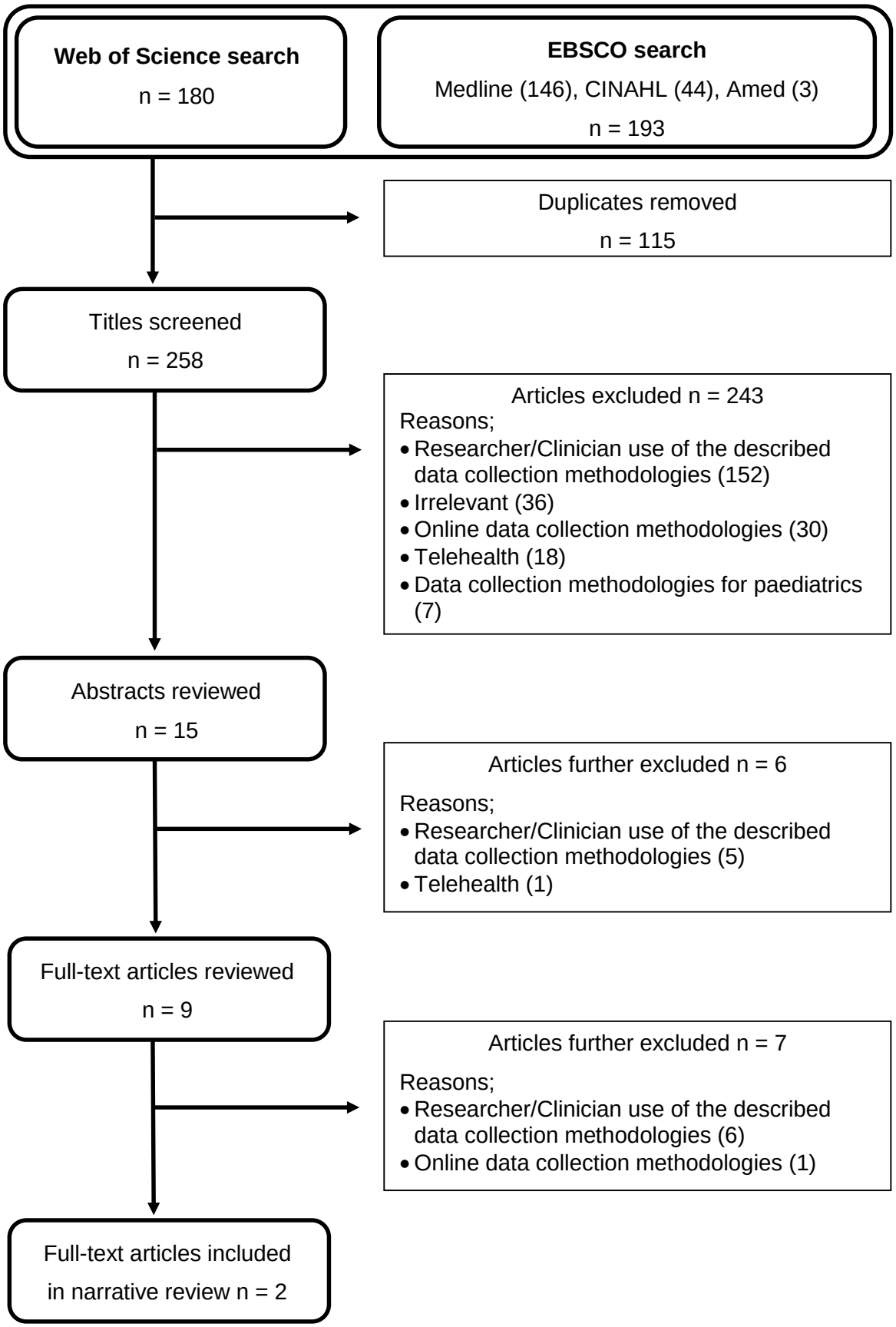
Following a search of databases described above using the outlined search strategy, identified publications were imported into ProQuest RefWorks (ProQuest, 2019). The citations identified through the systematic literature search were then screened by title, using the defined inclusion and exclusion criteria, by a single reviewer (SL). Any title identified as potentially relevant was carried forward to the abstract screening stage. The abstracts of titles that met the inclusion/exclusion criteria outlined in 4.3.3, were obtained for abstract review. Abstracts were then screened for full text review.

4.4 Results

The literature search identified a total of 373 articles and following the exclusion of 115 duplicates, 258 articles were title screened, 15 abstracts were reviewed and then 9 full text articles sought. 2 articles were finally identified for data extraction, following full text

screening. Figure 4.1 displays a flowchart summarising the number of articles excluded at each stage of the search.

Figure 4.1 Identification of articles for review



Of the 258 articles identified for screening, 163 (63%) articles were excluded, as they related to either researcher or clinician use of the described data collection methodology, as opposed to a data collection methodology for use by the participant. 36 (14%) articles were considered irrelevant for further review, 31 (12%) articles described online data collection methodologies, 19 (7%) articles were associated with telehealth captured data and 7 (3%) articles described data collection methodologies designed for paediatrics. There were just 2 (1%) articles that screened appropriate to be included in the final literature review, having met the specified inclusion criteria.

4.5 Quality assessment

Both articles included were assessed against a pre-set assessment tool by the author (SL) and a second reviewer (TH).

4.5.1 Quality assessment tool design

A quality assessment tool was designed using established tools and adapted to include factors specific to the objectives of this search. The Newcastle/Ottawa tool (Wells, et al., 2010) is recommended for use in assessing the quality of non-randomised studies and the AMSTAR 2 (Shea, et al., 2017) was developed to assess the quality of systematic reviews. Components of these were used, together with an additional point defined for the purposes of the thesis.

As the accessibility of the reviewed data collection methodology may have effects on participation, it was decided to include a measure on how well the articles addressed accessibility of data collection methodology exposure for participation.

The quality assessment tool used in this search, together with a description of where the individual points were taken from, is displayed in Table 4.2.

Table 4.2 Quality assessment criteria

Review Question	Awarded criteria	Non-awarded criteria
Selection		
1) Are the automated data collection methodology users the intended study participants?*	Yes	No / Unclear / NA
2) Do the automated data collection methodology users represent a generalisable primary care population?*	Yes	No / Unclear / NA
3) Are the number of primary care data collection locations enough to provide generalisable results?*	Yes	No / Unclear / NA
Comparability		
4) Were the strengths and limitations of the automated data collection methods described?*	Yes	No / Unclear / NA
Method of data collection		
5) Accessibility of automated data collection methodology equal for participants and non-participants?	Yes	No / Unclear / NA
Outcome		
6) Were response rates of the automated data collection methodology, calculated with a dominator representative of the whole eligible population?*	Yes	No / Unclear / NA
Bias		
7) Was the likelihood of publication bias assessed?[+]	Yes	No / Unclear / NA
8) Were any conflict of interest described?[+]	Yes	No / Unclear / NA

Key: ND = Not Documented / Unclear NA = Not Applicable

*Adapted from the Newcastle/Ottawa tool (Wells, et al., 2010)

[+]Adapted from AMSTAR 2 (Shea, et al., 2017)

4.5.2 Use of the assessment tool

Both reviewers agreed on whether the articles met, did not meet, were unclear or were not applicable. Points of disagreement were discussed, and a conclusive decision made. Table 4.3 shows the agreed assessment of article quality.

Table 4.3 Assessment of article quality

		Quality Assessment Criteria							
Author	**Reviewer**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Barr (2017)	1	+	+	-	+	+	+	+	+
	2	+	+	-	+	+	+	+	+
	Agreed	**+**	**+**	**-**	**+**	**+**	**+**	**+**	**+**
Pace (2005)	1	-	+	+	+	NA	NA	-	-
	2	-	-	+	+	NA	NA	-	-
	Agreed	**-**	**-**	**+**	**+**	**NA**	**NA**	**-**	**-**

Key: + = Criteria met, - = Criteria unmet (or unclear), NA = Criteria Not Applicable

4.6 Data extraction

A standard data extraction spreadsheet was set up using Microsoft Excel to extract relevant information from the articles identified including data relating to the; article type, study objectives, methods used, results and conclusions of the article; methods of data collection being discussed; and who the uses of the data collection methodology were.

Included articles were read to extract the information displayed in Table 4.4.

Table 4.4 Summary of articles reviewing the use of automated data collection methodologies

Author	Year	Location	Article type	Setting	Objectives	Methods	Methods of data collection described	Sample	Data collected
Barr P. *et al.*	2017	USA	Observational study	One primary care practice with a list size of 16,000 patients.	To test the delivery of a 3-item patient reported experience measure of Shared Decision Making (SDM) via different data collection methodologies. Data collection method response rates. Respondent characteristics across data collection methodologies.	Sequential administration of patient reported data collection methodologies, following a primary care consultation, over 15-months.	Paper Patient portal Interactive voice response (IVR) call Text (SMS) Tablet	Consecutive patients ≥18 years and parents / guardians of patients <18 years. n=4421	*Demographic data*: Age, gender, name of consulting clinician *Survey data*: 3 items on SDM
Pace WD. *et al.*	2005	USA	Review	Practice Based Research Networks (PBRN)	To describe the use of electronic methods of collecting data within practice based research networks.	Discussions with PBRN researchers Industry information Personal experience	• Personal computers • Networked computers • Notebook computers • Internet • Personal Digital Assistants (PDA)	Practice Based Research Networks	N/A

Author	Year	% Female	Average age	Limitations	Results of automated data collection	Outcomes
Barr P. *et al.*	2017	57.1%	49.57 years	Duration of recruitment period led to participant and organisational fatigue. Primary care staff were burdened by the modes of administration. Only one primary care setting used. The tablet was not altogether automated. A researcher needed to provide the patient with the data collection device and ask them to complete the survey. Study did not account for repeated visits and therefore the collection of repeated measures. Tablet methodology was costly.	Tablet computers administered by research staff had the highest response rates (41%). Those declining the tablet were given a paper-based survey for return in a postage-paid envelope. Patients were happy to participate once, but perceived little value in being asked again.	When selecting the mode of administration for a survey, patient experience is an important outcome measure. The decision for which administration mode is best for data collection will depend on whether data collectors can obtain patient information such as email addresses or telephone numbers to facilitate contact while maximising patient confidentiality or whether accessible automated data collection tools can be provided to and used by, the correct population.
Pace WD. *et al.*	2005	N/A	N/A	Based on PBRN experiences only. When developing an electronic data collection system, the following things need to be considered; hardware, software, network and work station requirements, personnel, and maintenance. Implications of these items on the primary care setting unavailable.	Tablet PCs offer portability, ease of use, autonomous use by patients, capability to store large amounts of data, display multimedia messages, are interactive at the point of care, and provide transparent decision algorithms, improved data entry and data integrity.	One electronic means of data collection will not meet all your needs. Administrative costs, practice burden and training must be considered when considering electronic data collection. Electronic methods of data collection contribute to data collected that can be efficient, of national scope and longitudinal.

4.7 Findings

The 2 articles identified include an observational study (Barr, et al., 2017) and a review (Pace & Staton, 2005). Whilst incomparable by study type, both articles provide some relevant and transferable findings. The automated data collection methodologies described in each article are discussed in detail next.

4.7.1. Key Findings

Published in the United States of America, both articles describe automated data collection methodologies employed for use in the primary care setting.

4.7.1.1 Barr PJ, *et al.*, 2017

Barr PJ, *et al*., 2017 describes clinician Shared Decision Making (SDM) performance, as rated by patients completing a 3-item patient reported experience measure of SDM (CollaboRATE), following any clinical consultation. Sequential patients were asked to complete a (non-clinical) 3-item measure of SDM performance via a range of data collection methodologies. Data collection methodologies included paper, online patient portal, Interactive Voice Response (IVR) call, text message and tablet computer. The automated tablet data collection methodology achieved the highest response rate (41%), however this data-collection method was also the costliest. The other methodologies provided response rates of; 12% (paper), 34% (online patient portal), 25% (IVR call) and 23% (text message). Whilst clinician SDM performance rankings were stable across the data collection methodologies, the response rates were sensitive to the data collection methodology. This article highlights that when selecting the method of data collection for a survey, it seems that patient experience and patient burden are important outcome measures. Response rates to the associated paper survey were 12% and to email and tablet computer were 34% and 41% respectively, supporting the view that technological methods yield improved response rates, provided respondent burden is avoided (Hood, et al., 2012).

Whilst meeting seven out of the eight quality assessment criteria, the main limitation of this article was that data collection was only conducted in one practice. Both the practice setting and the practical challenges encountered of; competing administrative priorities, information systems and staffing availability, may have contributed to sampling biases. Conducting this survey across multiple practices would have been one way to ensure more generalisable outcome data, not skewed by practice, geographical and population idiosyncrasies.

Unlike the research methodology to be employed for the purposes of this thesis, patient participation in the CollaboRATE study was not altogether automated. An eligibility assessment was conducted manually by a researcher, who would then ask the eligible patient to complete the CollaboRATE survey via the provided data collection methodology. The number of patients completing the CollaboRATE survey over the 15 months of data collection was n=4,421. The length of the study though, led to participant, researcher and practice fatigue. Staff were burdened by paper survey tasks and they received reports that patients who had previously completed the CollaboRATE survey perceived little value in repeating their evaluation.

4.7.1.2 Pace WD and Staton EW, 2005

Pace WD and Staton EW, 2005 describe the use of electronic methods of collecting data within Practice Based Research Networks (PBRN). PBRNs are groups of primary care clinicians and practices in the United States of America, '*working together to answer community-based health care questions and translate research findings into practice'*, to improve the health of Americans (AHRQ, 2018). The article is based on the findings from: the examination of a convenience sample of literature on PBRNs that have used electronic data collection methods and discussions with PBRN researchers; industry information; and the personal experiences of the authors.

The specification of each data collection methodology discussed, is detailed in depth. Due to the date that this article was published, 2005, many of the limitations described are now no longer relevant for consideration today. Limitations included the variability in hardware and software available, connectivity problems and the substantial start-up effort, to include ongoing training and support that would be required in primary care. Digital advancements have remedially solved the described limitations although interestingly, whilst this article expresses that, "*the introduction of enhanced technology during the past decade has heightened researchers' expectations of electronic data collection*", this statement is still valid for use in an article today. Despite there being significant advancements in our digital infrastructures across the world over the last 15 years, further novel developments are always awaited.

Notably, the first recommendation the article makes highlights how important limitation of burden on the participant is. Pace and Staton identify the logistical and practical advantages that handheld computer technology such as tablets offer including portability, ease of use, autonomous use by patients, the capability to store large amounts of data, can display multimedia messages, are interactive at the point of care, and provide transparent decision algorithms, improved data entry and data integrity. Together these qualities reduce the administrative cost and burden on all involved in the conduct of research, to improve response rates for observational studies.

Training was a limitation consideration described in this article, however developments in technology since 2005, and the use of devices much more widely have led to the introduction of intuitive devices to ensure technology is much more accessible used more widely. Technological developments now provide us with data collection methodologies which can support the very same advantages envisaged 15 years ago; "*data collection that can be efficient, of national scope and longitudinal".*

The reference list from identified citations within this article were reviewed for other additional publications that were potentially relevant. The articles identified related to Information Technology (IT) capabilities, IT infrastructure and the introduction of innovative technologies, for the time. Pen-tablet computers for collecting data were described as, allowing patient-directed data collection at a single point in time, which patients were willing and able to use (Main, Quintela, Araya-Guerra, Holcomb, & Pace, 2004).

4.7.2. Summary of the relevant literature

The overall aim of this systematic literature search and narrative review, was to identify and summarise the published literature exploring the autonomous patient use of data collection methodologies used within primary care health settings for the purposes of research.

There is a significant risk that the collection of research data from patients, outside of the consulting room, but during their visit to a primary care setting, could potentially be viewed as a burden by participants, where surveys are lengthy and administered out of context (Barr, et al., 2017). Barr *et al.* (2017) suggest however, that these challenges can be overcome with the use of only a minimum number of data collection items.

The literature infers that automated methods of data collection will provide strong response rates. Testing the generalisability of these findings across multiple primary care settings though, is now important. There is also a need to investigate whether automated data collection tools can be provided to, and used by, the target population, while maximising patient confidentiality. The subsequent data collection, analysis and visualisation of the data will also be important, in order that the results can facilitate the core purpose of providing timely feedback, to improve clinical practice.

In addition, the methods of participant identification described in the literature reviewed, do not account for repeated participant measures, unlike the research methodology to be employed for the purposes of this thesis, which will.

4.7.3. Evaluation of the methods used

This section brings together the summarised findings and will review the strengths and limitations of the systematic literature search and narrative review.

4.7.3.1. Strengths

The focal strength of this systematic literature search and narrative review was the systematic approach that was employed to ensure that all articles relevant to the objectives of this thesis, were included. Search terms were appraised by systematic review experts, to ensure an unbiased and comprehensive literature search. An assessment of the methodological quality of each article included for review was made using elements of recognised quality assessment tools. The two articles from which data were extracted, were dually quality assessed by reviewers, SL and TH. Data extraction was also undertaken twice (SL and TH) to minimise any human error during the extraction of data.

4.7.3.2 Limitations

The aim of the literature search was to identify methodologically similar studies to the one being proposed for this thesis. From the articles identified it is clear that the use of technology, automated for use by potentially eligible participants in a primary care setting, identifying eligible participants, and collecting subsequent data, for inclusion in a research study, has not previously been reported in the mainstream health literature. Identified articles were limited to those written in English. Whilst the systematic literature search may have benefitted from having no language limits, the risk of a significant article being missed

that would have greatly affected the findings was potentially low, given that the articles identified were from around the world.

The articles were also limited to those describing research conducted in a primary care setting only. It was felt that this was an important criterion, as it had been identified that primary care has a unique place in the NHS in England (NIHR, 2019), with other settings being incomparable.

4.8 Discussion

There is very little evidence available in the literature to describe the collection of research data using automated devices, within primary care settings. There is no evidence to suggest that the collection of additional patient data for research purposes using automated check-in screens has previously been investigated in this setting. Success of a new data collection initiative is based on the methodology being acceptable and feasible to its users. The method must also overcome barriers to behaviour change (Bradbury, et al., 2017).

Given the limited availability of other literature in this field, the two articles reviewed do provide us with some evidence to suggest that automated technologies, for use by patients, are acceptable for data collection. Further exploration of patient acceptability for providing additional data for the purposes of research whilst specifically, self-completing an automated check-in screen within a general practice waiting room, needs to be piloted and investigated.

The following chapter describes the methodologies used, to develop the research study for investigating the use of an automated check-in screen system to collect brief self-reported patient research data within the general practice setting. This will include a description of the study design, how data will be collected, the use of Patient and Public Involvement and

Engagement (PPIE) in the design and conduct of the study, and the process of obtaining the relevant regulatory approvals to carry out the research.

5 METHODS

"We keep moving forward, opening new doors, and doing new things, because we're curious and curiosity keeps leading us down new paths."

— Walt Disney

This chapter details the design of the research study, the methods used to conduct the empirical data collection and the methods used to analyse the data. The consultation processes exercised to gain approval of the research procedures are also described.

5.1 Study design

"A feasibility study asks whether something can be done, should we proceed with it, and if so, how. A pilot study asks the same questions but also has a specific design feature" (Eldridge, et al., 2016). This pilot descriptive cross-sectional study has been described as such, due to its unique and innovative data collection methodology. The intended use of a general practice automated arrivals check-in touchscreen is to confirm a patient's arrival for a booked appointment, with seamless integration to the patients' electronic medical record. An additional feature of the check-in system to be piloted, will be the nascent use of the system to collect additional brief research data.

The term 'pilot' is a suitable descriptive for the small-scale test of the new methodology being employed to collect brief research data from participants. A 'pilot' study can be described as a requisite step to exploring whether the results from a novel application can then be used to inform 'feasibility' (Leon, Davis, & Kraemer, 2010). The feasibility of future studies using this unique and innovative data collection methodology will be answered by this pilot study as it will provide an answer to the question, *"Can this study be done?"* (NIHR, 2018). The study design is a 'descriptive cross-sectional' study, as it measures the

prevalence of response on a representative sample of a general practice population who have been questioned over a short period of time (Bowling, 2014).

The research study designed was entitled, '**A**utomated **C**heck-in **D**ata **C**ollection Study' or the 'AC DC Study'.

5.1.1 Site participation

Selected general practices within the National Institute of Health Research (NIHR) Clinical Research Network (CRN): West Midlands (WM) whose General Practice System of Choice (GPSoC) is Egton Medical Information Systems (EMIS Web), were asked to host the two research questions on their automated check-in screen, for a period of 3-weeks recruitment per practice, to assess if the automated check-in screens can also be used for brief research data collection. Three consecutive weeks of recruitment per practice, was agreed by both practice managers and the AC DC Study team, as being sufficient to provide a representative picture of general practice activity and would allow for the thorough testing of the new methodology.

Those practices operating GPSoC EMIS Web were selected to participate as currently, only EMIS Web has the add-on facilities to enable the addition of bespoke, end-user defined questions. The participating general practices' EMIS Web system required Egton Automated Arrival facilities to include a Questionnaire Module and an automated arrivals check-in touchscreen. This enables any answer to a displayed question to be coded with a Read code (a code taken from a thesaurus of clinical terms) or SNOMED-CT code (Systematized Nomenclature of Medicine Clinical Terms, a unique 'concept ID' for a clinical term) (NHS Digital, 2018), applied directly into the patient record without the need for administrative input. The study Health Informatics Specialist (SW) coordinated the installation of the required software in participating practices (where a Questionnaire

Module was not already available) and programmed the automated arrivals screen to provide the research questions, in line with the study protocol.

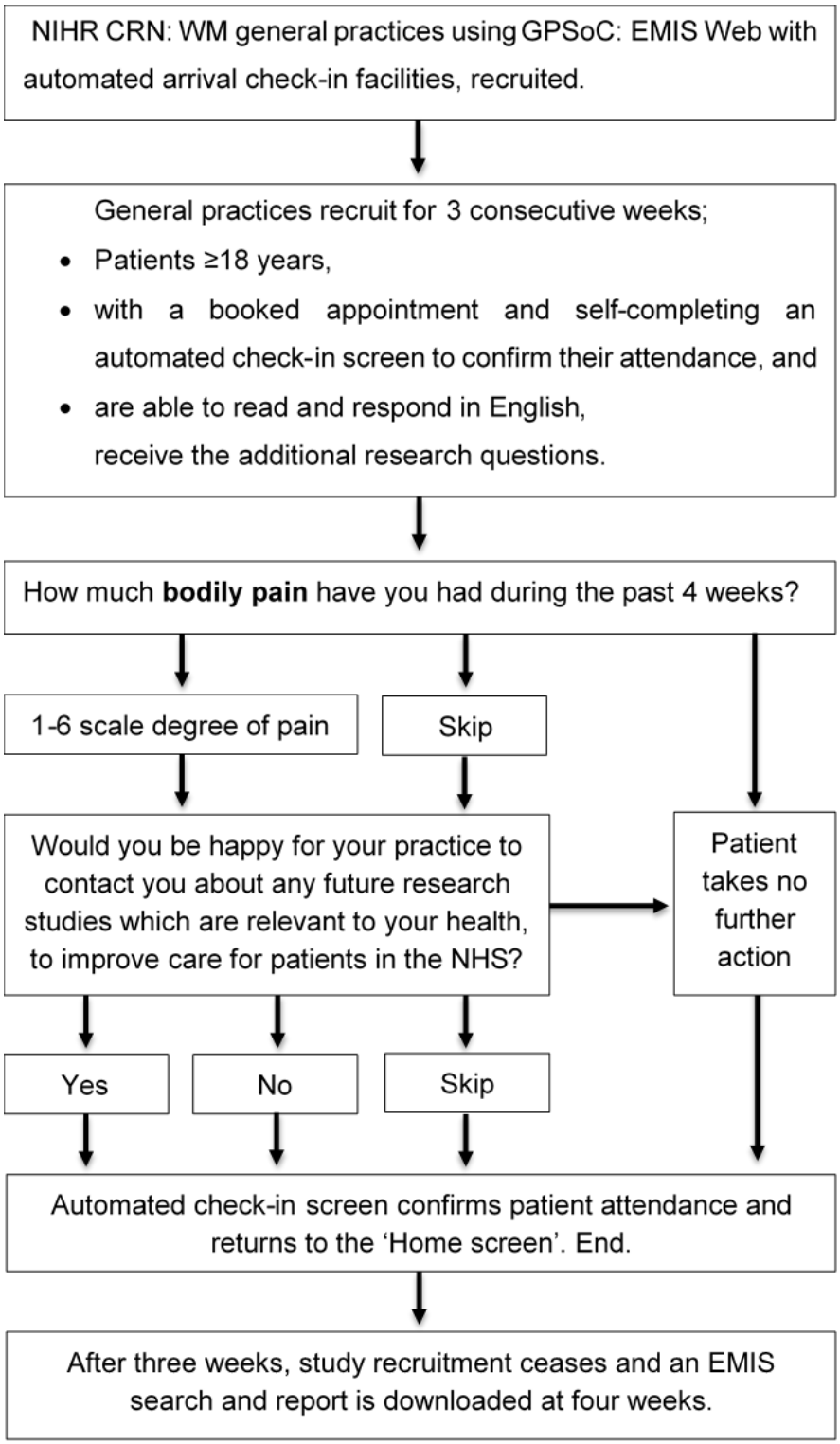
5.1.2 Patient identification

Patients book appointments with multiple Healthcare Professionals (HCP) at their registered general practice by either telephoning the practice and booking an appointment, physically attending the practice and booking an appointment or by booking appointments using the practice on-line services (if available). The management and administration of this process at a general practice, is coordinated by the Practice Manager alongside the practice administration team. Once patients attend for their booked appointment, the automated check-in screen provides efficiencies for the practice administration team, as patients are empowered to self-check-in.

During the recruitment period for each participating practice, all patients 18 years of age or over and able to read and respond in English, attending for a booked appointment and completing an automated check-in screen confirming their attendance, were eligible to participate in the study, see Figure 5.1.

Figure 5.1 AC DC Study Flowchart

Flow chart demonstrating recruitment of participants into the study.



The study was advertised at each participating general practice during their 3-week recruitment period. An invitation poster (see Appendix 2 Participant Invitation Poster) was

displayed alongside the automated check-in screen, providing brief information to patients on the research study being conducted. This included the inclusion criteria for participation and where more information could be sought, if the participant required. Participant Information Leaflets (PIL) (see Appendix 3 Participant Information Leaflet) were also made available at the check-in screens, for patients to take away if they wished. The PIL provided details on how patients could withdraw or change any information provided for the study and contained the contact details for the AC DC Study team, should the patient wish to ask any questions about the study or clarify the research process before deciding whether or not to participate. Following a patient using the automated check-in screen to confirm their attendance for a booked appointment, the research questions appeared for completion. Only once the research questions had either been answered, 'skipped' or sufficient time had elapsed without a response (30 seconds), did the check-in screen provide confirmation of the patient's attendance. Participant recruitment to the study was therefore autonomous. There was no requirement for a researcher to be present in order for recruitment and data collection to occur.

5.1.3 Patient consent

Consent to participate in this cross-sectional study was obtained, in line with the definition outlined in Article 4(11) of the General Data Protection Regulation (GDPR) guidance, "*any freely given, specific, informed and unambiguous indication of the data subject's wishes by which he or she, by a statement or by a clear affirmative action, signifies agreement to the processing of personal data relating to him or her*" (European Parliament, 2016). As such patient consent to participate in the study was implied by question completion.

5.2 Data collection

In order to answer the objectives, data was required from two sources; the Questionnaire Module responses contained within EMIS Web and descriptive observations noted by administrative staff in a daily diary.

5.2.1 Questionnaire Module

The Questionnaire Module is additional software designed to gain patient data on their health, including clinical information (e.g. smoking status) or demographic data (e.g. ethnicity), whilst they are confirming their arrival for a booked appointment through the automated check-in screen.

This software enables a general practice to design their own questionnaires and assign the appropriate clinical Read/SNOMED code for the associated responses. Once a question is answered by a patient using the automated check-in screen, the corresponding Read/SNOMED code is then filed back to the patients' medical record. The clinical codes can then be searched for within the clinical system and actioned as required. The specification of each questionnaire can also be configured as such that the regularity of questionnaire completion can be defined.

Two items of self-reported brief research data were required for collection from participants self-completing an automated check-in screen, prior to a booked general practice appointment. The number of questions asked of patients whilst checking in for a booked appointment was limited to just 2, on recommendation from EMIS Health (EMIS health, 2019) to avoid queues at the check-in screen and patient apathy. The process of checking in usually takes <1 minute to complete. Answering two research questions in addition during this process, can also be completed in <1 minute. On discussion with our Patient and Public Involvement and Engagement (PPIE) members (see section 5.4) it was agreed that a

maximum of 2 research questions should be asked. Their reasons included, the avoidance of creating a queue at the check-in screen due to the time taken to complete the extra questions and as an impact of a potential queue forming, loss of confidentiality in the provision of responses.

5.2.1.1 Research questions

The subject and format of research questions can impact on completion rates (Newington & Metcalfe, 2014). For this reason, and to maximise completion of responses, this pilot descriptive cross-sectional study includes both a 'bodily pain' research question and a 'contact about research' question.

5.2.1.1.1 'Bodily pain' research question

Chronic pain affects around 20% of the population and those with chronic pain consult their general practitioner around 5 times more frequently than those without (Royal College of General Practitioners, 2013). Increasingly, patients are living with multiple, long-term chronic conditions, both physical and psychological - and at the same time general practitioners are being asked to do more routine health checks, ask more questions and give more advice as standard during consultations. The standard 10-minute appointment is simply inadequate to deal with this (Irving, et al., 2017). Pain is commonly neglected by patients and not prioritised by general practitioners. Although effective pain management interventions and programmes exist, provision of these services is inconsistent, and chronic pain is not given the priority it requires in view of the extent of its burden on individuals and society (Phillips, et al., 2008). A prompt about bodily pain for patients to complete at checking in for a booked appointment at the general practice, might encourage them to highlight this in a consultation. The data collected can additionally be entered straight into the patient's medical record and can facilitate the impending appointment, making an efficient use of the consultation.

Valid and reliable assessment of pain is essential, to assess impact on wellbeing, functioning and lifestyle, however the nature of pain makes objective measurement incredibly challenging (Breivik, et al., 2008). Validated research tools to measure pain were reviewed, together with commonly used measures of health status. In order to ask one general question about patient experiences of pain, example questions were taken to the PPIE group, where the wording of the question was agreed (see section 5.4).

The first research question to appear on the check-in screen after completion of demographic details (as standard) was;

"How much bodily pain have you had during the past 4 weeks?"

With options for completion of;

"None", "Very mild", "Mild", "Moderate", "Severe", "Very severe"

or

"Skip question"

5.2.1.1.2 'Contact about research' question

The invitation to voluntarily participate in healthcare research and the conversion rate into participants recruited for research is variable. As previously discussed, many factors can affect and impact on recruitment success rates. Collecting data on whether patients are happy to be contacted about research could provide general practices with efficiencies in resource (by targeting those who are more likely to participate), improved accuracy in sampling and by providing patients with more control of how their data are used (those who do not want to participate or share their data will not be contacted). The EU GDPR replaced the Data Protection Directive 95/46/EC on 25th May 2018 and following Brexit on 1st January 2021, the UK has incorporated UK GDPR into law. As part of this regulation there is the right of the data subject to obtain from the data controller, confirmation as to whether or not personal data concerning them is being processed, where and for what purpose (Schulz & Hennis-Plasschaert, 2016). General practices are data controllers of patients'

(data subjects) healthcare data. This legislation allows data subjects to have control over how their data is processed by the controller. This enables patients therefore, the ability to indicate whether they consent to the practice inviting them to voluntarily participate in research.

A prompt for patients to complete at automated check-in, with regards to whether the patient would be happy to be contacted by the practice about any future research of relevance to them, would provide the patient with some control over how their data is being used by the general practice and clarify whether or not a patient would be willing to be contacted about research or not. Again, the data collected through this process is entered directly into the patient's medical record and can facilitate how personal data is used by the general practice. The wording for this question was designed by the PPIE group.

The second research question to appear on the check-in screen was;

"Would you be happy for your practice to contact you about any future research studies which are relevant to your health, to improve care for patients in the NHS?"

With options for completion of;

"Yes, I'd be happy for you to contact me about research of relevance to me",

"No, thank you"

or

"Skip question"

5.2.1.2 Routing

How the questions appear depends on the settings with which they are assigned. This is important; for the effective management of the data flow; for interpretation, and analysis; and for the patient experience. The selection of the 'Skip question' response simply sends

the participant onto the next section, whether that be the next question or confirmation of check-in attendance.

If the patient took no further action once the first research question had appeared, then the check-in screen awaited a response and after sufficient time had elapsed without a response (30 seconds), the automated check-in screen returned to the 'Home' screen, after confirming check-in attendance for the booked appointment. The second question was not displayed.

If the patient answered the first research question but took no further action once the second research question appeared, the check-in screen awaited a response and after sufficient time had elapsed without a response (30 seconds), the automated check-in screen returned to the 'Home' screen, after confirming check-in attendance for the booked appointment. The data collected for the first research question only, was recorded (see Figure 5.1).

5.2.1.3 Data extraction

A series of psuedonymised data extractions were developed by the study Health Informatics Specialist (SW). Within the EMIS Web record management system, a Reporting Module provides the user with customised detail about the data contained within the system. A 'Search' is used to identify a population of patients with a specific set of criteria, and 'Reports' are used to report on features of those patients identified. Search and Reports were developed for all booked appointments scheduled and attended at the general practice during the 3-week recruitment period at each participating practice, for patients of age 18 years or older. The data extractions, whilst based on the dates specified for the recruiting period of each practice, were not run until day 28 of recruitment. This provided up to four weeks for any affirmative action taken by participants to be amended. All data extractions were run by the Practice Manager and then securely transferred to the School for Primary,

Community and Social Care[2], Keele University. The data was password protected and stored on secure university servers.

Three separate Search and Reports were developed;

1. **AC DC – 18+ Demographics**

   Search: identified all patients registered at the practice on [DATE (day 21 of recruitment)]

   Report: provided the number of registered patients identified in the Search, split by all documented categories of gender and then further by;

   - older than or equal to 18 years and younger than or equal to 34 years
   - older than or equal to 35 years and younger than or equal to 49 years
   - older than or equal to 50 years and younger than or equal to 64 years
   - older than or equal to 65 years and younger than or equal to 79 years
   - older than or equal to 80 years

   Purpose: to enable patient demographic data to be used as a stratifying variable for analysis.

2. **AC DC – Appointments Report**

   Search: identified all patients with a booked appointment from [DATE (day 1 of recruitment)] to [DATE (day 21 of recruitment)]

   Report: provided the booked appointments identified in the Search with;

   - Appointment date and time
   - Slot Type *e.g. Follow-up, Book-on-the-day*
   - Arrive Time to Send In Time
   - Current Slot Status *e.g. Left, DNA, Visited*

[2] School for Primary, Community and Social Care was re-named, School of Medicine on 1st August 2020.

Purpose: to explore question completion rates depending on the time difference between; check-in completion and booked appointment time.

3. **AC DC – Questionnaire Responses**

   Search: identified all AC DC questionnaire responses from [DATE (day 1 of recruitment)] to [DATE (day 21 of recruitment)]

   Report: provided the responses to the two AC DC research questions

   Purpose: to obtain the response data to the two AC DC research questions

For all patients for whom the AC DC research questions appeared, an additional data extraction was obtained from the Egton Questionnaire Module software, which could be performed remotely by the Health Informatics Specialist, using [DATE (day 1 of recruitment)] to [DATE (day 21 of recruitment)] as parameters;

[PRACTICE NAME] LogReport

This was a psuedonymised report detailing check-in screen use;

- for confirmation of attendance
- for questionnaire completion

Each data extraction also contained unique patient check-in ID (system user / practice), to form the psuedonymised extraction and for the reports to be linked. These extractions formed the basis of the quantitative data collection. See Table 5.1 for data items and from where the quantitative data was collected.

Table 5.1 Data items and method of data collection

Data items	Description	Method of data collection
Patient demographics	Gender	EMIS data extraction
	Age	
Date and time of:	Check-in	
	Appointment	
Check-in ID	'System user' or 'Practice' ID	
Degree of bodily pain experienced during the past 4 weeks.	Single question: 1-6 point scale – degree of pain	Patient self-reported
Consent to contact about future research studies of relevance.	Dichotomous: Yes or No	

5.2.2 Daily diary

Any check-in queries made to practice administration staff by patients as a result of the two AC DC research questions appearing on the patient automated check-in screen, were anonymously logged, to assess the impact of check-in completion for general practice operationalisation. A daily diary of queries received was populated for a total of 4 weeks. Three weeks during recruitment to the cross-sectional study and for one week following the end of recruitment.

5.3 Sample size

EMIS Web is the clinical system of choice used by 67% of practices across the NIHR Clinical Research Network: West Midlands (CRN WM) footprint (Kontopantelis, et al., 2018). This equates to 652 general practices with a population of approximately 4,890,000 patients. The average patient list size of research active general practices in the CRN WM north region is 7,500 patients, of which approximately 6,000 (80%) will be 18 years of age or over. The minimum recommended number of appointments provided per week, per 1,000 patients is 72 (British Medical Association, 2016). Assuming the same rate of appointment

use in those under and over 18 years, an average of 432 appointments per week for those aged 18 years of age or over, can be expected. Over a recruitment period of three-weeks, discounting an approximate 10% of patients who have either; more than 1 appointment booked within the three-week period, lack capacity to complete the automated check-in screen, or the appointment is for either a telephone appointment or a home visit, each participating practice will potentially provide approximately 1,166 eligible participants.

One of the objectives of this cross-sectional study, as discussed in Chapter 2, is to estimate the number of patients who would be happy for their practice to contact them about any future research which are relevant to their health. Assuming that approximately 50% will respond positively to this question, 9604 people will need to respond to the question in order to estimate a 95% confidence interval for this proportion formally with a precision of 0.01.

Assuming that 80% of those who use the automated check-in screen complete the additional research questions, this would require 12005 people to complete an on-screen check-in in order to achieve sufficient responders and study power. This number of potential responses to the two AC DC research questions will provide a crude proxy of patient acceptability for completing two research questions in the general practice waiting room whilst autonomously checking in, per practice. This participant sample size equates to the requirement of approximately 11 average sized general practices displaying the two research questions for 3-weeks each, although this number is dependent on variations in practice size and actual use of the automated check-in screens.

One diary for logging patient check-in queries per participating practice, was completed by practice administration staff. A record of queries received, as a result of the two AC DC research questions appearing on the automated check-in screen for completion, would allow a qualitative assessment of the impact that the research questions had on automated check-in completion for general practice operationalisation.

5.4 Patient and Public Involvement and Engagement (PPIE)

In the UK there has been a clear policy directive to involve patients and the public in research (NHS Executive, 1999). More recently, the UK Policy Framework for Health and Social Care Research (NHS HRA, 2020) has set out principals to promote the interests of patients, service users and the public, in health and social care research. PPIE will lead to research that is of greater relevance and of better quality (Tomlinson, Medlinskiene, Cheong, Khan, & Fylan, 2019) to stakeholders. Keele University have an established Research User Group (RUG) made up of volunteer patients, who provide advice and feedback on study/trial conduct and offer patient and public representation on studies.

5.4.1 PPIE consultation

During April 2018, 8 patients from Keele's RUG accepted an invitation to assist with the development of the AC DC Study. The patients attended a group meeting held at the School for Primary, Community and Social Care, at Keele University. The session was facilitated by SL, together with the study Health Informatics Specialist (SW) who was also present to take notes and advise on question routing needed to develop the survey. The intention of the meeting was to explore patient acceptability for answering two research questions whilst confirming attendance for a booked appointment, using an automated check-in screen in a general practice setting. The AC DC Study was presented to the group to provide them with; background information; aims and objectives of the cross-sectional study; an explanation of the methodology for collecting the research data; and they were also provided with the proposed AC DC research questions. The group were then able to assist the design of the cross-sectional study as described in the next sections.

5.4.1.1 Documentation

The patient facing documentation (Participant Invitation Poster, see Appendix 2 and Participant Information Leaflet, see Appendix 3) developed for the study was co-developed

with the PPIE group. They were asked to consider the documents in terms of content, layout, wording, style and length. The documents were agreed and approved without amendment. Feedback suggested that wording was appropriate, was brief enough not to cause hold-ups at the check-in screen but was also detailed enough to enable patients to make informed decisions about whether they wished to take part in the AC DC Study.

5.4.1.2 Question development

The wording of the AC DC research questions, together with their associated options for completion, developed by the study team, were then posed to the group. The patients were asked to consider the wording and the order of the questions. On reading the question options provided to them, there was cohesion of opinion that the first research question should be the 'bodily pain' question and the second research question be the 'contact about research' question. They considered that this would provide a smoother flow to the two questions, which were not particularly linked in any way to each other. The patients agreed that the questions needed to be brief and easy to answer, quickly. They were in agreement that asking only 2 or a maximum of 3 research questions would be appropriate, there would not be time for more than this.

The following options for wording the first question were provided to the patients;

"How much bodily pain have you had during the past *n(number) d*(days) *w*(weeks)?"

Or

"How would you rate your pain on a 0-10 scale at '*a given point in time*', where '0' is no pain and '10' is pain as bad as could be?"

With options for completion of;

"None", "Very mild", "Mild", "Moderate", "Severe", "Very severe"

Or

"0", "1", "2", "3", "4", "5", "6", "7", "8", "9", "10"

What *'pain'*, the questions referred to though was a discussion point. Different interpretations of the word 'pain' were explained by the group as, 'bodily', 'physical', 'joint', 'muscular' or 'emotional' pain. As the group began breaking down '*what pain?'* the question may be referring to, they also considered confidentiality. Whilst imagining that they were answering the questions on a check-in screen in the waiting room of their general practice, there was then consensus which demonstrated that most patients would interpret the word 'pain' to be that of 'generalised' pain' and they agreed that *'bodily pain'* should be the preferred wording to match this descriptor.

The PPIE group felt that the timespan over which patients needed to consider their experiences of pain, was of importance. Suggestions of time ranged from 'within the last 24 hours' to 'over the last 6 months'. The literature was investigated for optimal recall periods for patient reported outcomes and it was identified that recall periods of the same day and up to 4 weeks made very little difference to responses (Broderick, et al., 2008). The options suggested were discussed and it was agreed that, in order to provide a snapshot of pain which could be interpreted as an average of the pain experienced, over a timescale they could accurately recall, 4 weeks was agreed. The 1-6 point scale descriptors were favoured as response options, over the numerical rating scale. Patients felt that this provided them with more intuitive, descriptive options to select from, as opposed to simply selecting a number. The number rating was interpreted as being impersonal and not a measure they could relate to.

The following options for the wording of the 'contact about research' question were then provided;

"Would you be happy for us to contact you about any future research studies which are relevant to your health?"

Or

"Would you be happy for us to provide the School of Primary, Community and Social Care (SPCSC) at Keele University with your contact details in order that they can invite you to participate in any future research studies which are relevant to you your health?"

With options for completion of;

"Yes, I would be happy for you to contact me", "No, thank you", "Skip question"

Or

"Yes, I would be happy for you to provide my contact details to SPCSC in order that I can be invited to participate in research of relevance to me", "No, thank you", "Skip question"

Again, the patients agreed that the questions needed to be brief, to enable them to be answered quickly. The longer questions and options of response they felt, would require more consideration and as a result, more time. They did not feel that these were appropriately styled for the environment in which the questions would need to be answered. The group agreed that the patients would want to feel comfortable about the answers they were providing. One patient described it as, *"I'd want to feel like my doctor was asking me personally".*

The group concurred that the briefer question should be used, with additional wording to provide; assurance that it was the general practice that was asking the question; that it would only be for research of relevance to them personally; and what the overall aim for asking the question was. The following wording (with the agreed changes highlighted in bold text) was therefore agreed;

"Would you be happy for **your practice** to contact you about any future research studies which are **relevant** to your health, **to improve care for patients in the NHS**?"

With options for completion of;

"Yes, I'd be happy for you to contact me about **research of relevance to me**",

5.4.1.3 Data collection processes

The feedback obtained from the PPIE group, to ensure that the presentation, content and functionality of the research were acceptable and appropriate for use within a general practice setting, was invaluable. Discussion was held around the process of data collection. Confidentiality and time taken to complete was discussed at length, however patients felt that completing the check-in screens was probably more discreet than talking to a receptionist and the patients behind you overhearing any conversation.

The other consideration was health and safety, particularly in terms of hygiene. Use of a touch screen in an environment where there may be contagious illnesses was a concern. The concerns however were considered proportional with those to include, opening of doors, holding onto railings etc., and so considered as being insignificant by comparison. It was also noted that the majority of practices have hand gels and sanitisers available for patient use both before and after check in screen use.

5.4.1.4 Dissemination of results

The PPIE group requested that the results from the pilot-feasibility cross-sectional study, be presented back to the wider RUG, as they were eager to be informed of the response rates that the AC DC research questions obtained. They also agreed to be involved in any amendments that might be required should the study methodology be rolled out further, for future research.

5.4.2 PPIE recommendations

The recommendations provided during the meeting were invaluable and were implemented into the final wording agreed for the AC DC Study protocol, which were regulatory approved. The PPIE recommendations for content, style, wording, length of questions, interpretation of text, layout and length of documentation are all important variables for consideration.

Interpretation taken from the PPIE input alone, into the design of a study, could theoretically be provided in such detail that it would require its own thesis. The information collected from the PPIE involvement gained on the design of the AC DC Study though, was felt sufficient for the complexity associated with the cross-sectional study.

5.5 Regulatory approvals

Health Research Authority (HRA) approval is the process for the NHS in England that brings together the assessment of governance and legal compliance, with independent Research Ethics Committee opinion provided through the UK Health Departments' Research Ethics Service. These regulatory approvals were applied for and sought, for the collection and analysis of two pieces of research data. The two pieces of research data were collected from patients, attending for a booked appointment at their general practice, at the point of automated check-in. Approvals also included the collection of associated operational and demographic data, and were sought before the AC DC Study commenced.

5.5.1 Ethical Approval

The study was submitted to and approved by London - Westminster Research Ethics Committee (REC) under proportionate review and the appropriate Site Specific Assessor for each participating site prior to entering participants into the study. Following approval from the REC, the REC were updated of the study progress in line with reporting requirements.

5.5.1.1 Provisional Opinion

A provisional favourable opinion of the AC DC Study was provided on 16th August 2018, against version 1.0 of the study protocol. The REC were content to provide a favourable ethical opinion of the research, subject to clarification of three points raised by the

committee during their review. The points raised and the responses provided were as follows;

1. Confirm whether or not a screen, prior to the study research questions, could be added that asks patients if they wish to take part in the research and offering them the chance to say yes or no.

a. If this is possible, please provide the text you will use.

b. If this is not possible, explain how you will ensure that people have enough time to make an informed decision on participating in the study and will not have the decision taken away from them because they do not respond in time.

Response: The research team have considered your suggestion to include a question which asks patients whether they wish to take part. The same time frame for a response to this question would again apply though, without resolving the issue you highlight. We have discussed with, and taken recommendations from the automated check-in software suppliers, that 2 additional questions added to the check-in screen are the maximum number of questions to ensure highest completion rates. Given the suggested wording amendments made to the Participant Invitation Poster and the information provided on how any involvement can be amended or withdrawn, the research team now feel that patients will have adequate time to make an informed decision on participation. The two AC DC research questions will also appear on subsequent patient appointment check-in screens during the recruitment period, for those participants who do not respond to the questions at their first opportunity.

As the sub-committee also noted, to avoid incurring any delays for patients checking in, the research team would like to keep the number of questions asked to a minimum, an additional question would however be possible.

2. In the "What is the purpose of this study" section of the Participant Information Sheet, make it clear that the study is investigating patients' acceptance of being asked study research questions when they check-in at the GP practice.

Response: Amended as suggested.

3. On the invitation poster: change "Study" to "Research Study", change "you may be asked extra questions" to "if you are 18 or over you may be asked extra questions." And after "We will appreciate if you could answer" add "If not, you can still check-in as normal once the questions disappear."

Response: Amended as suggested.

5.5.1.2 Favourable Opinion

Following response to the provisional opinion, a favourable opinion was provided by the London - Westminster Research Ethics Committee on 30th August 2018, against version 1.0 of the study protocol, see Appendix 4. HRA approvals were then obtained on 24th September 2018, see Appendix 5.

5.6 In-practice testing

Following the receipt of regulatory approvals, in-practice testing was conducted at the first participating general practice site, during practice closure time and with dummy participants, according to version 1.0 of the study protocol.

During testing, it was identified that should a patient ignore the first research question, they were not then provided with opportunity to answer the second research question. Instead, the check-in screen returned to the 'Home' screen, confirming the patient's attendance. At this point it was identified that an additional response option of, 'Skip', would provide the

patient with access to the second research question, in cases where they did not wish to answer the first, 'bodily pain' focussed question.

Following investigation with the software provider, an EMIS Health software update had implicated the original design for the operational flow of the study. The addition of the 'Skip' option however, was now beneficial as it provided the patient with access to the second research question, together with choice around whether or not they were to participate in the research study.

All possible scenarios for completion of the check-in screen were tested during the in-practice testing phase. The remaining tests passed. Following the approval of a substantial amendment to amend the routing, the study was ready to 'go live' and commence formal participant recruitment.

5.7 Substantial amendment

Following the in-practice testing for the study, it was recognised that the addition of a 'Skip' option would be necessary in order to provide potential participants with access to the second research question, due to a software update of the Questionnaire Module having implications for the operational flow of the study.

Amendment AM01 was compiled and submitted for regulatory approvals on the basis of the following justification, together with version 2.0 of the study protocol and associated documentation;

"Data for this study is being collected using the Egton Questionnaire Module for use in conjunction with GP practice EMIS Web record management systems. EMIS health have updated their software which has had implications for the operational flow of this study. The amendment provides patients with more choice as to whether or not they participate in the

study, with the inclusion of a 'Skip' option for response. In addition, a few administrative amendments have also been made as part of the submission for this amendment."

On 19th December 2018, the members of the London - Westminster Research Ethics Committee taking part in the ethical review of the substantial amendment AM01, agreed that the changes were acceptable and provided a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation, see Appendix 6. In conjunction, the HRA categorised the amendment as a Category C amendment (Health Research Authority, 2019), indicating that the changes could be implemented immediately and the study commenced, in accordance with version 2.0 of the study protocol.

5.8 Statistical methods

Simple descriptive statistics were used to characterise the study sample first and then to compare potential demographic differences between responders and non-responders. This is a descriptive study with frequencies and percentages of responses to the 2 questions determined, stratified by age, gender and practice. Mean or median times (as appropriate) between check-in and time of being called into the appointment will be calculated in responders and non-responders separately. IBM SPSS Statistics 24 was the statistical software used to analyse the data. In the production of and reporting on subgroups, ONS guidance were followed on statistical microdata, to ensure the confidentiality of individual persons is protected (Office for Statistics Regulation, 2018).

Thematic content analysis, a descriptive presentation of qualitative data (Bowling, 2014), was to be used, if appropriate, to interpret the participant data logged by practice administrative staff. From the data collected, categorical themes will be identified, and then weight and relevance attributed, based on quantification rather than interpretation.

5.9 Summary

This chapter has summarised and justified the methods used to develop the AC DC Study. The following chapter describes the results of the data obtained from the pilot-feasibility descriptive cross-sectional study.

6 RESULTS

“The thing I love about data is finding out something new and different”

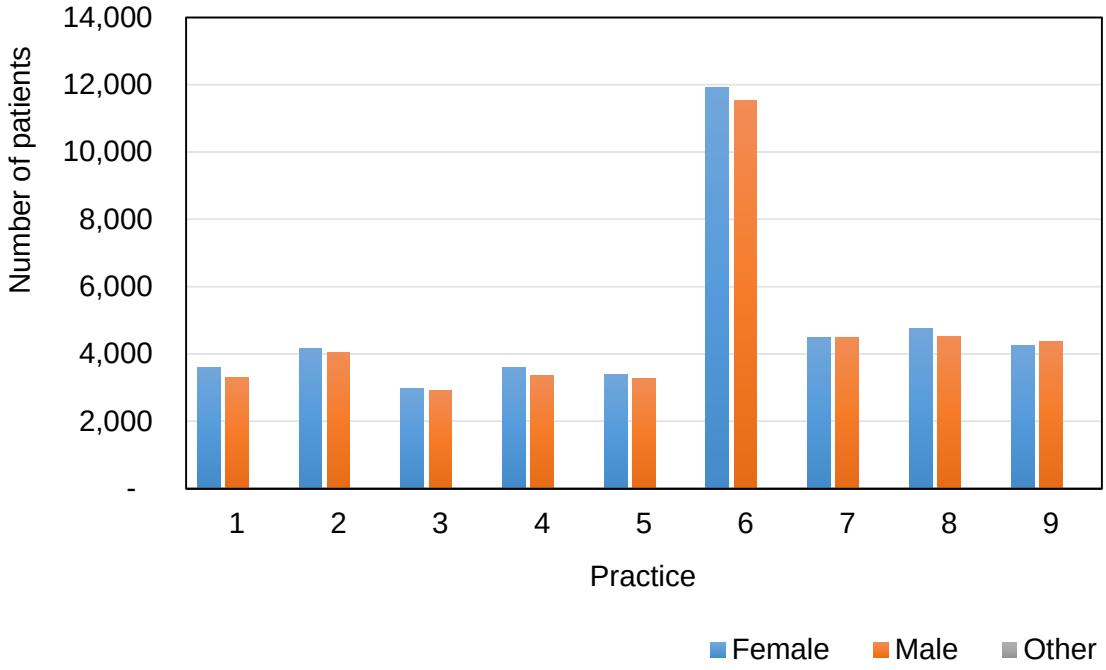
— Peter C. Doherty

This chapter presents the results of the AC DC Study. The characteristics of the sample population and participant group are presented, followed by the responses to the fixed response questions.

6.1 Study population

9 general practices within NIHR CRN: WM, whose General Practice System of Choice (GPSoC) is Egton Medical Information Systems (EMIS Web) were identified. These 9 practices provided a total population of 84,976 patients aged 18 years of age or over (50.8% (n=43,134) Female; 49.2% (n=41,841) Male; 1 Other). 11 practices were not therefore required, as per sample size calculations, as one of the practices identified had a practice list size almost comparable to three average sized practices. The median practice size was 8,211 patients with an interquartile range of 6,782 – 9,127 patients, and range of 5,901 – 23,449 patients. Figure 6.1. displays the practice population, aged 18 years of age or over, for each participating practice.

Figure 6.1 Practice population



6.2 AC DC eligibility population

The data presented in Table 6.1 displays;

- the practice (population) patient demographics of those 18 years of age or over,
- the practice potentially eligible (patients with a booked appointment during the recruitment period) patient demographics, and
- the number of eligible patients (those using the automated check-in facilities), to confirm their attendance for their booked appointment.

Table 6.1 AC DC eligibility data

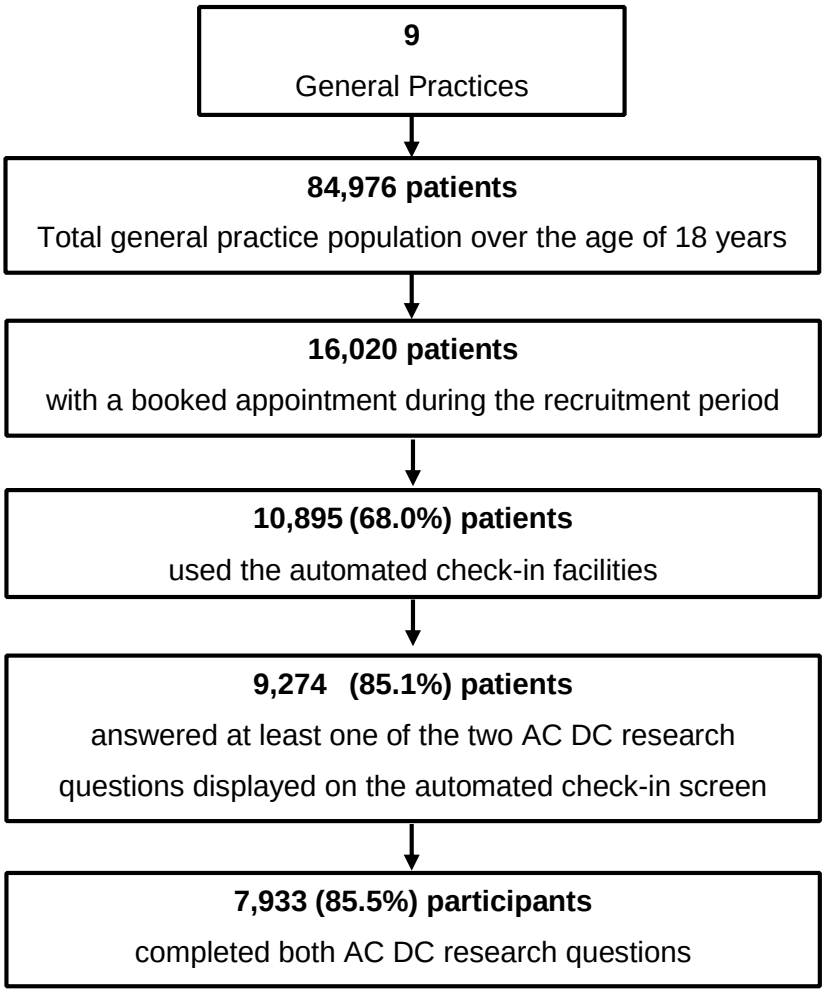
Practice population data				Demographic characteristics of all potentially eligible patients (those with booked appointments during the recruitment period)				Number of eligible patients (those using the automated check-in facilities)
General practice list size*		Gender % (Females)	Age (years) Mean	Number of patients	Gender % (Females)	Age (years) Mean (S.D)	Age (years) Range	% (n)
1	6,906	52.2% (3,606)	57.0	(n=1,539)	59.2% (912)	61.1 (18.9)	18 – 98	82.1% (1,264)
2	8,211	50.6% (4,154)	50.8	(n=1,384)	60.2% (834)	52.9 (18.8)	18 – 94	84.6% (1,171)
3	5,901	50.4% (2,974)	54.2	(n=1,246)	57.4% (722)	57.8 (18.2)	18 – 96	86.3% (1,075)
4	6,976	51.8% (3,614)	52.4	(n=1,444)	62.1% (897)	58.3 (19.4)	19 – 98	69.0% (996)
5	6,657	50.9% (3,390)	52.6	(n=1,253)	61.0% (764)	56.9 (19.4)	18 – 96	73.0% (915)
6	23,449	50.8% (11,910)	52.7	(n=4,390)	61.0% (2,676)	58.3 (19.0)	18 – 102	58.9% (2,586)
7	8,977	50.0% (4,492)	48.9	(n=1,506)	59.4% (894)	51.6 (19.0)	18 – 98	58.6% (882)
8	9,277	51.2% (4,751)	51.3	(n=1,855)	61.2% (1,136)	55.0 (19.0)	18 – 96	61.2% (1,135)
9	8,622	49.2% (4,243)	50.0	(n=1,403)	58.8% (825)	56.2 (19.3)	18 – 93	62.1% (871)
Totals	**84,976**	**50.8% (43,134)**	**52.1**	**(n=16,020)**	**60.3% (9,660)**	**56.8 (19.2)**	**18 – 102**	**68.0% (10,895)**

*List size as at day 28 of recruitment

6.3 AC DC Study participation

Invitation to participate in the AC DC study was provided for 68.0% of all potentially eligible patients. 85.1% of these eligible patients then went on to participate in the AC DC Study, see Figure 6.2.

Figure 6.2 Summary of AC DC Study participation



Participation in the study was obtained from 57.9% (n=9,274) of all potentially eligible patients with a booked appointment (n=16,020).

6.3.1 Baseline demographics

During the study recruitment period 10,895 patients used the automated check-in facilities. Of these, 85.1% (n=9,274) participated by answering at least one of the two research questions displayed on the automated check-in screen. Baseline demographics of participants versus non-participants, is summarised in Table 6.2.

Ongoing data monitoring however identified that one practice (practice 5) had a lower than expected participation rate. Following investigation of the Questionnaire Module software settings at this practice, it was identified that 'Force Survey' had not been activated and the 'Time out' setting for question display time had been set at just 10 seconds. Identified on day 10 of recruitment, these settings were rectified and recruitment resumed immediately. This resulted in a reduction in the number of eligible patients able to participate at this practice. Practice 5 is therefore an outlier, removing practice 5 from the analyses results in a participation rate of 89.2% (n=8,903).

The age and gender distribution of participants (85.1% (n=9,274)) versus the non-participants (14.9% (n=1,621)) can be seen in Table 6.2. There was no variation in age of the participants versus non-participants, however the proportion of non-participant females (64.8%), was marginally higher than the proportion of females with a booked appointment during the recruitment period (60.3%) and of those using the automated check-in facilities (61.5%).

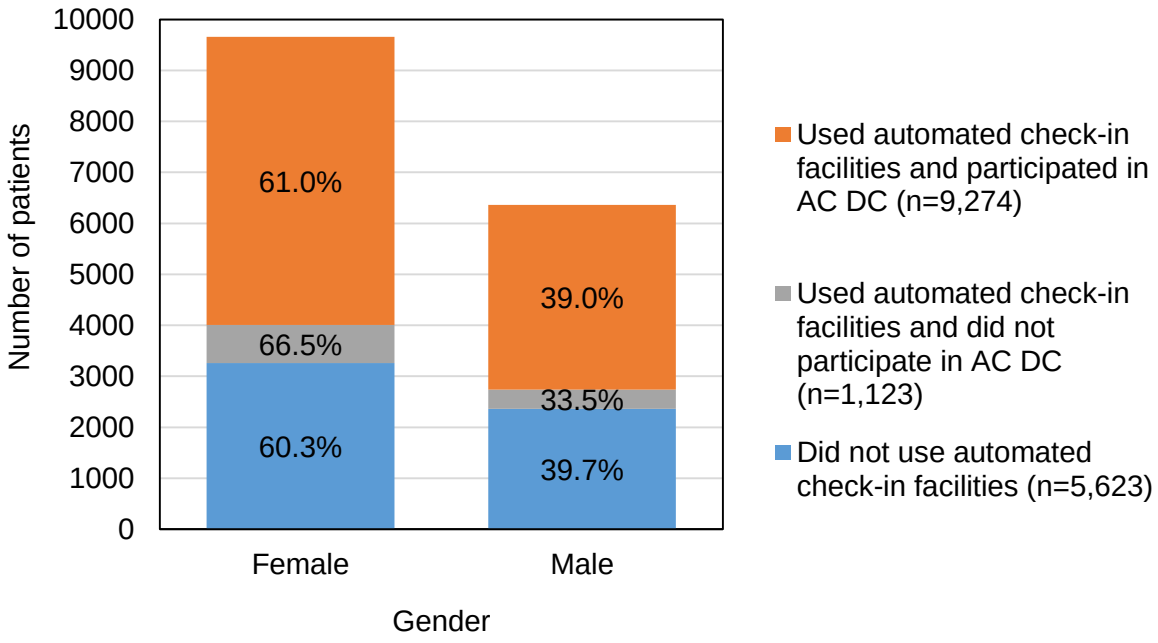
Table 6.2 Demographics of participants and non-participants.

Demographic characteristics of study participants and non-participants (n=10,895)									
GP	% (Number of patients)				**Gender** % (Females)		**Age** (years) Mean (S.D)		Range
1	**Participants**	86.9%	(1,099)		58.7%	(645)	59.8	(18.5)	18 – 97
	Non-participants	13.1%	(165)		64.8%	(107)	66.3	(19.2)	18 – 98
2	**Participants**	93.7%	(1,097)		61.4%	(674)	52.0	(18.0)	18 – 95
	Non-participants	6.3%	(74)		59.5%	(44)	47.0	(20.2)	18 – 82
3	**Participants**	84.0%	(903)		59.6%	(538)	56.8	(17.8)	18 – 95
	Non-participants	16.0%	(172)		58.7%	(101)	58.4	(19.2)	18 – 92
4	**Participants**	91.2%	(908)		60.2%	(547)	55.7	(19.8)	19 – 95
	Non-participants	8.8%	(88)		69.3%	(61)	57.2	(19.8)	21 – 88
5	**Participants**	40.5%	(371)		64.2%	(238)	54.2	(18.9)	19 – 96
	Non-participants	59.5%	(544)		60.8%	(331)	54.3	(19.2)	18 – 93
6	**Participants**	90.4%	(2,339)		61.2%	(1,432)	56.5	(18.5)	18 – 97
	Non-participants	9.6%	(247)		70.4%	(174)	60.9	(18.5)	18 – 96
7	**Participants**	80.3%	(708)		60.0%	(425)	49.5	(17.7)	18 – 98
	Non-participants	19.7%	(174)		71.8%	(125)	48.1	(18.6)	18 – 94
8	**Participants**	95.3%	(1,082)		64.4%	(697)	53.1	(18.1)	18 – 91
	Non-participants	4.7%	(53)		71.7%	(38)	49.6	(19.8)	18 – 86
9	**Participants**	88.1%	(767)		59.6%	(457)	54.0	(18.4)	18 – 93
	Non-participants	11.9%	(104)		66.3%	(69)	49.9	(21.8)	18 – 89
	Participants	**85.1%**	**(9,274)**		**61.0%**	**(5,653)**	**55.1**	**(18.5)**	**18 – 98**
	Non-participants	**14.9%**	**(1,621)**		**64.8%**	**(1,050)**	**55.7**	**(20.0)**	**18 – 98**

6.3.2 Gender

Given a total participating practice population of 84,976 patients, 50.8% were registered as female and 60.3% of all eligible patients with booked appointments during the recruitment period were female. 61.0% of AC DC Study participants were female, as were 66.5% of non-participants. This is illustrated in Figure 6.3.

Figure 6.3 Attendance management by gender



6.4 AC DC research question responses

85.5% (n=7,933) of participants completed both AC DC research questions. 10.7% (n=989) completed only the clinical research question and 3.8% (n=352) completed only the 'contact about research' question. There were no significant differences when the data were stratified by practice or by gender. This detailed analysis can be found in Appendix 7.

6.4.1 'Bodily pain' research question

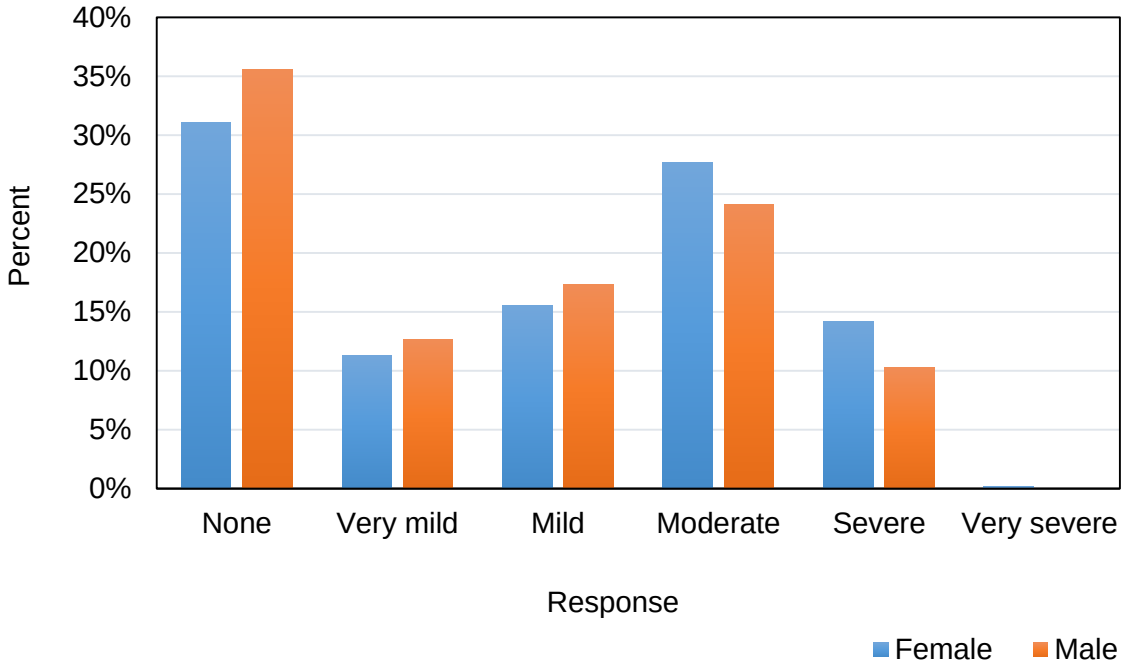
96.2% (n=8,922) of participants answered the 'bodily pain' research question, "How much bodily pain have you had during the past 4 weeks?". Table 6.3 presents a summarised analysis for the responses provided and Appendix 8 presents the detailed analysis of the responses provided.

Table 6.3 Reported bodily pain during the past 4 weeks

Practice	(number of responses)	Response %(n)											
		None		Very mild		Mild		Moderate		Severe		Very Severe	
1	1,037	35.0%	(363)	14.2%	(147)	16.9%	(175)	23.5%	(244)	10.4%	(108)	0.0%	(0)
2	1,051	28.9%	(304)	8.9%	(94)	15.1%	(159)	29.1%	(306)	17.8%	(187)	0.1%	(1)
3	825	31.6%	(261)	13.7%	(113)	16.8%	(139)	22.7%	(187)	15.2%	(125)	0.0%	(0)
4	878	32.9%	(289)	10.0%	(88)	16.2%	(142)	28.1%	(247)	12.6%	(111)	0.1%	(1)
5	347	35.4%	(123)	11.0%	(38)	15.9%	(55)	24.5%	(85)	13.3%	(46)	0.0%	(0)
6	2,229	35.0%	(781)	13.3%	(297)	15.9%	(354)	24.9%	(555)	10.8%	(240)	0.1%	(2)
7	706	30.0%	(212)	10.8%	(76)	17.1%	(121)	29.2%	(206)	12.7%	(90)	0.1%	(1)
8	1,082	31.4%	(340)	10.0%	(108)	16.5%	(179)	29.1%	(315)	12.7%	(137)	0.3%	(3)
9	767	34.4%	(264)	13.0%	(100)	15.9%	(122)	25.9%	(199)	10.6%	(81)	0.1%	(1)
Totals	**8,922**	**32.9%**	**(2,937)**	**11.9%**	**(1,061)**	**16.2%**	**(1,446)**	**26.3%**	**(2,344)**	**12.6%**	**(1,125)**	**0.1%**	**(9)**
Age Group													
18 – 34	(n=1,547)	42.3%	(654)	12.0%	(185)	19.5%	(301)	18.3%	(283)	7.7%	(119)	0.3%	(5)
35 – 49	(n=1,791)	32.9%	(590)	11.7%	(209)	18.2%	(326)	25.0%	(447)	12.2%	(219)	0.0%	(0)
50 – 64	(n=2,413)	28.4%	(685)	11.4%	(275)	15.7%	(380)	29.5%	(711)	14.8%	(358)	0.2%	(4)
65 – 79	(n=2,364)	31.3%	(739)	11.9%	(282)	14.1%	(333)	29.1%	(687)	13.7%	(323)	0.0%	(0)
80+	(n=807)	33.3%	(269)	13.6%	(110)	13.1%	(106)	26.8%	(216)	13.1%	(106)	0.0%	(0)
Totals	**8,922**	**32.9%**	**(2,937)**	**11.9%**	**(1,061)**	**16.2%**	**(1,446)**	**26.3%**	**(2,344)**	**12.6%**	**(1,125)**	**0.1%**	**(9)**
Gender													
Female	5,386	31.1%	(1,677)	11.3%	(611)	15.5%	(836)	27.7%	(1,491)	14.2%	(762)	0.2%	(9)
Male	3,536	35.6%	(1,260)	12.7%	(450)	17.3%	(610)	24.1%	(853)	10.3%	(363)	0.0%	(0)
Totals	**8,922**	**32.9%**	**(2,937)**	**11.9%**	**(1,061)**	**16.2%**	**(1,446)**	**26.3%**	**(2,344)**	**12.6%**	**(1,125)**	**0.1%**	**(9)**

The distribution of responses for reported bodily pain over the last 4 weeks did not vary by age, although females reported higher levels of moderate, severe or very severe pain than males, see Figure 6.4.

Figure 6.4 Bodily pain reported over the last 4 weeks



39.0% (n=8,922) of participants (42.0% (n=2,262) of females and 34.4% (n=1,216) of males) reported having moderate to very severe bodily pain during the past 4 weeks.

6.4.2 'Contact about research' question

89.3% (n=8,285) of participants answered the 'contact about research' question, "Would you be happy for your practice to contact you about any future research studies which are relevant to your health, to improve care for patients in the NHS?".

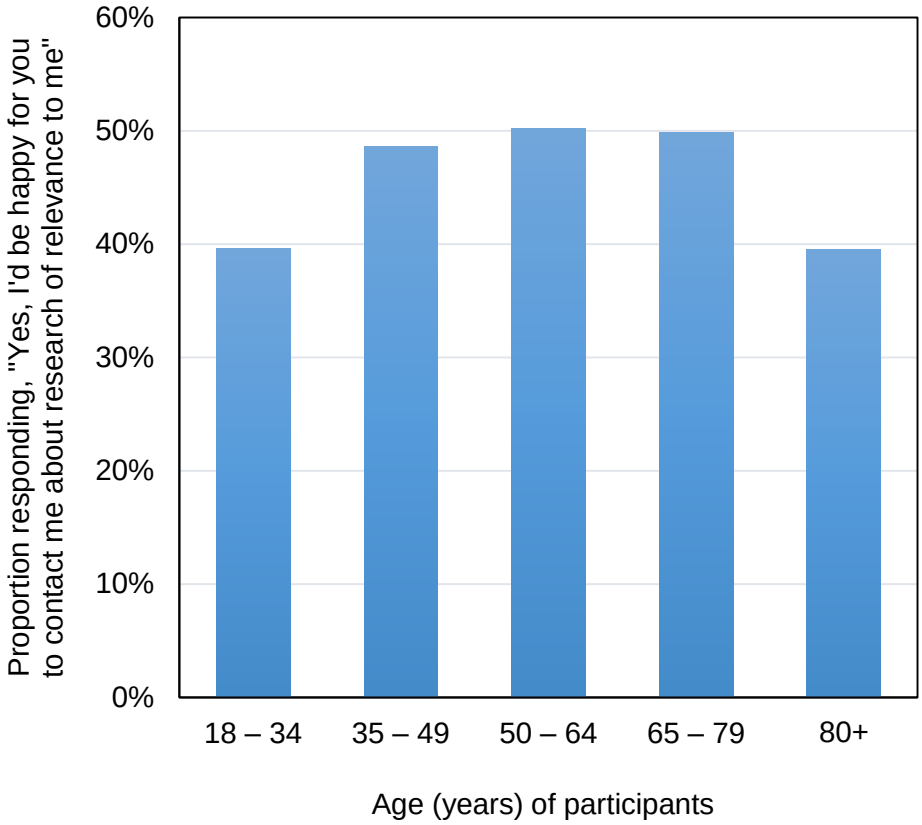
46.9% (n=3,889) of participants responded, "Yes, I'd be happy for you to contact me about research of relevance to me". This response varied very little by practice or gender. Table 6.4 illustrates the detailed results for the responses provided.

Table 6.4 Response to the 'contact about research' question

	(n)	Response: "Yes, I'd be happy for you to contact me about research of relevance to me"	
		%	(n)
Practice			
1	(976)	48.6%	(474)
2	(996)	46.3%	(461)
3	(767)	51.6%	(396)
4	(823)	43.6%	(359)
5	(336)	50.6%	(170)
6	(2,082)	46.4%	(966)
7	(583)	48.2%	(281)
8	(1,041)	46.6%	(485)
9	(681)	43.6%	(297)
Totals	**(8,285)**	**46.9%**	**(3,889)**
Age group			
18 – 34	(1,531)	39.6%	(607)
35 – 49	(1,715)	48.6%	(834)
50 – 64	(2,249)	50.2%	(1,128)
65 – 79	(2,109)	49.8%	(1,051)
80+	(681)	39.5%	(269)
Totals	**(8,285)**	**46.9%**	**(3,889)**
Gender			
Female	(5,054)	47.0%	(2,374)
Male	(3,231)	46.9%	(1,515)
Totals	**(8,285)**	**46.9%**	**(3,889)**

The proportion of participants responding, "Yes, I'd be happy for you to contact me about research of relevance to me" presents a normal distribution though, with those in the youngest and eldest range ranges least likely to be happy to be contacted, see Figure 6.5.

Figure 6.5 Age range response to the 'contact about research' question



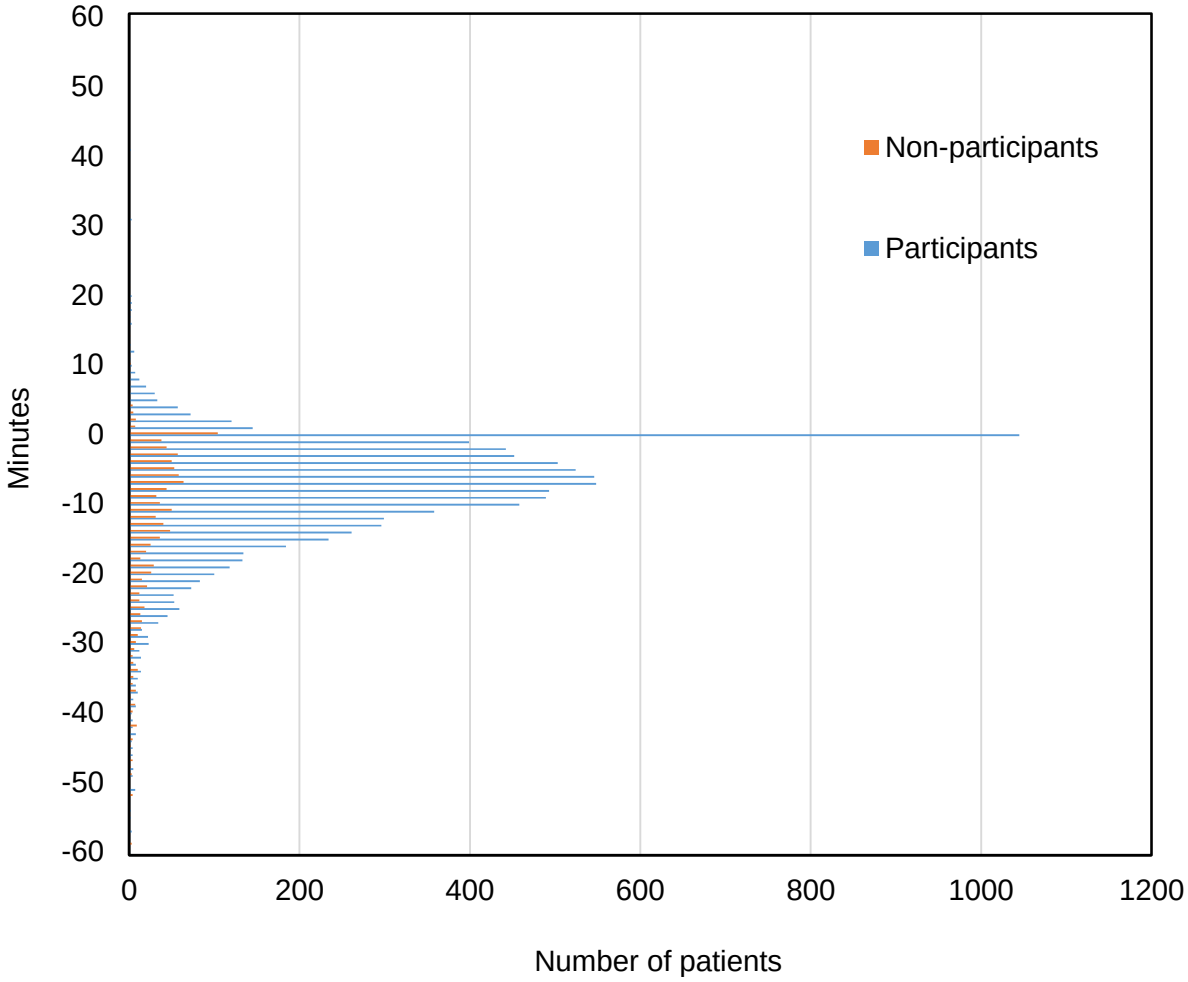
6.5 Time available for participation

The number of minutes that patients checked in either in advance of their booked appointment time or after their booked appointment time is shown, stratified by participants (n=9,166) versus non-participants (n=1,159), in Figure 6.6.

Both participants' and non-participants' mode for time of check-in, was at 0 minutes or at the scheduled appointment time. Participants checked in a median of 7.0 minutes before the booked appointment, IQR 12.0 – 2.0 minutes before the booked appointment; and non-participants checked in a median of 10.0 minutes before the booked appointment, IQR 18.0 – 4.0 minutes before the booked appointment.

General practices had programmed their automated arrivals screen with a time frame for patients to book in, to cover arrivals in advance or after a booked appointment time. This time frame varied by practice and unfortunately the time frame was not standardised by practice. A range of 60 minutes either early or late for a booked appointment was collected and anything outside of this range was excluded. For practices which had programmed a narrow time frame for patients to check-in, there were missing data in the extracted data reports.

Figure 6.6 Check-in time data



NB. Check-in at the scheduled appointment time is displayed at 0 minutes. Check-in before the scheduled appointment time (early) is displayed by results plotted in the negative y-axis values.

6.5.1 Missing data

Of those patients using the automated check-in facilities (n=10,895), check-in time data was not available for 1.2% (n=108) of participants and 28.5% (n=462) of non-participants.

6.5.2 Time available effect on participation

25.7% (n=2,649) of patients checked in for their booked appointment within three minutes of their booked appointment time or after their booked appointment time (late) (26.5% (n=2,430) of participants and 18.9% (n=219) of non-participants).

6.5.3 Time available effect on reported pain score

Checking in for a booked appointment, within three minutes of the booked appointment time or after their booked appointment time (late), did not have an effect on the distribution of responses reported for bodily pain over the last 4 weeks, see Table 6.5.

Table 6.5 Time available effect on reported pain score

Reported bodily pain	All participant responses (n=8,922)		Participant responses of those checking in within three minutes of the booked appointment or after their booked appointment time (late) (n=2,335)	
	N	(%)	n	(%)
None	2,937	(32.9%)	758	(32.5%)
Very mild	1,061	(11.9%)	282	(12.1%)
Mild	1,446	(16.2%)	409	(17.5%)
Moderate	2,344	(26.3%)	603	(25.8%)
Severe	1,125	(12.6%)	279	(11.9%)
Very severe	9	(0.1%)	4	(0.2%)

6.5.4 Time available effect on ‘contact about research’ decision

The proportion of participants responding, "Yes, I’d be happy for you to contact me about research of relevance to me" when checking in less than three minutes, or ‘late’, for a booked appointment 44.5% (n=963), was also comparable to the overall response rate to this question 46.9% (n=3,889).

6.6 Effect on practice operationalisation

Any check-in queries, made to practice administration staff by patients, as a result of the research questions appearing on the patient automated check-in screen, were anonymously logged in a daily diary, to assess the impact of check-in completion for general practice operationalisation. All diaries were returned after 28 days of recruitment and 2 diaries had a total of 3 entries documented.

6.6.1 Descriptive observations

Diary entries included;

“8:23am: Questions are looping, not allowing check-in. Delayed check-ins”

“8:30am: Resolved”

“16:42pm: Patient wishes to change their mind to the second question, EMIS updated”

“9:50am: Check-in screen not finding patients”

On further discussion with EMIS Web, they confirmed that ‘questions looping’ may have been a short-term issue which was resolved automatically by the system. This problem was rapidly resolved automatically within 7 minutes of the problem being identified and did not cause any long term operational disruption to the practice.

It was only documented once that a patient wished to change their mind on how they answered a research question. The practice administrative staff were able to update the response and this issue was resolved quickly.

For the last observation, on further investigation, it may have been that the patient did not actually have a booked appointment on that day.

In summary, the addition of two research questions to 9 practices' automated check-in screen and the recruiting of 9,274 research participants to the AC DC Study, has only generated 3 'observations'. The operational disruption caused by including some brief research data collection at the point of automated check-in could be considered negligible.

6.7 Summary

This chapter has presented the results of the AC DC Study.

The main findings are that 89.2% of those patients using the check in screen proceeded to participate in the AC DC Study, answering at least one of the two research questions. The proportion of participants completing both research questions was 85.5% (n=7,933), with 96.2% of participants answering the 'bodily pain' question and 89.3% participants answering the 'contact about research' question.

The distribution of responses for reported bodily pain over the last 4 weeks, did not vary by age. Females reported higher levels of moderate, severe or very severe pain than males, although this was not statistically significant (95% CI: 3.32–3.37; p=0.1096). 46.9% of participants responded, "Yes, I'd be happy for you to contact me about research of relevance to me".

The time available, prior to booked appointment time, to check-in using the automated check-in screen did not appear to affect responses and the use of the check-in screen neither had any operational impact on the practice.

The data obtained from the AC DC Study, provides strong evidence to fulfil and resolve the cross-sectional study objectives. These results will be explored in more detail in the next chapter to enable the provision of feasibility information for the future use of automated check-in screens as an innovative data collection methodology, for the collection of brief patient self-reported research data. The results are next discussed and related to the methods and features of the cross-sectional study and the results of other studies, where relevant.

7 DISCUSSION

“In the middle of difficulty lies opportunity.”

— Albert Einstein

This chapter will build on the previous by discussing the reported results obtained from the conduct of the pilot-feasibility descriptive cross-sectional AC DC Study. The results are discussed with reference to the methods and previous work presented in this thesis.

7.1 The utility of check-in screens to collect brief research data

The aim of this thesis was to investigate the utility of using an automated check-in screen as a research tool in providing brief research information, whilst self-completing an automated check-in screen, prior to their unsolicited general practice appointment (which from now on will now be referred to as the AC DC methodology). Of those patients that used the check-in screen, almost ninety percent (89.2%) participated, answering at least one of the two research questions displayed. In section 3.2.2.3, Figure 3.1 provides an infographic developed by Lindemann 2019 (Lindemann, 2019) which combines study response rates, to illustrate how variable response rates to surveys can be. This infographic however implies that those methods with minimal human interaction, using technology enabled methods of data collection, have lower response rates than others. In addition, Lindermann concludes that the average response rate that could be expected from a survey, is just 33%. Use of the AC DC methodology to collect brief research data in the AC DC Study, has far exceeded this published average response rate. Even the 57% response rate that Lindermann reports at best, for ‘In-person surveys’, is exceeded by the results of the AC DC Study, however this must be interpreted with caution, as the number of parameters associated with the AC DC methodology, as with other data collection

methodologies, influence response rates. It is important therefore that these are examined further.

7.1.1 Check-in screens to collect quantitative data

The use of automated check-in screens to collect data for quantitative health research, has advantages and disadvantages. The general advantages and disadvantages of data collection methodologies as identified previously in section 3.2, can now be applied to the use of automated check-in screens.

7.1.1.1 Advantages

Relative low cost

The costs today associated with a traditional postal survey to gain 9,274 participants (assuming a response rate of 50% (Lindemann, 2019), with one mailing, using second class postage at a large letter rate) would be approximately £26,710 (not including administrative costs to include: printing, preparing a mailing, data entry and the quality assurance monitoring that will need to run simultaneously with these processes). In comparison, the cost for the check-in hardware (to include cabling), software and Questionnaire Module installation per practice is approximately £3,200 + VAT. For 9 practices, this is £28,800 + VAT. Whilst the prices are comparable for a one-off survey, the cost efficiencies would be gained by using the check-in facilities for multiply surveys. Many general practices however, are already utilising the check-in screen hardware. Purchase of the Questionnaire Module alone to install with existing hardware would cost approximately £345 + VAT per practice (£3,105 + VAT for nine practices) providing a much lower cost methodology than a traditional postal survey.

Convenience

Postal surveys involve patients completing a questionnaire and then posting the return response. General practices encourage patients to complete an automated check-in screen, in order to confirm their attendance for a booked appointment. Answering additional research questions that appear on the screen at the same time, does not add any extra burden to participants and they are familiar with the process. This can be evidenced by the results, with 89.2% of those patients presented with the opportunity to participate in the AC DC Study, answering at least one of the research questions.

Large geographical area sampling

Egton Medical Information Systems (EMIS Web) is used by 56% of practices across England (NHS Digital, 2018). If all practices, with the appropriate software module, were to add research questions to their automated check-in screens, a large geographical area for sampling could be obtained. Flexibility and specificity of area sampling to target certain geographical populations could also be achieved.

Rapid data collection

The recruitment period for the AC DC Study was just 3-weeks. 9 practices participated, which resulted in the recruitment of 9,274 participants. The AC DC Study utilised a new innovative methodology for the collection of research data. Only one or two practices were 'live' and recruiting participants at any one time. In future, if data is collected across general practices in parallel, the results obtained for the AC DC Study provide evidence for the feasibility of extremely rapid data collection.

The AC DC Study was also very easy to set-up. The study did not require the researcher to visit the practice. The general practice automated arrivals software could be programmed remotely with the research questions. Data extraction was also performed by the practices

running a study designed Search and Report for the data variables of interest. Electronic transfer of data enabled results to be obtained quickly.

Can target specific populations

At present, the Questionnaire Module software (as part of the Egton Automated Arrival facility) can only trigger a survey based on a specified age range and gender, of eligible patients. Specific geographical populations can also be targeted. The ability to target a more specific patient population (e.g. males, over 60 years old, with diabetes) though, using the software is limited. Expanding the software eligibility inclusion criteria however, is an area of development that we have engaged EMIS software architects to work with us on. The hope is that surveys will be able to be triggered based on a diagnostic clinical Read/SNOMED code the software finds in the patient's electronic medical record. In the meantime, the software could be used at specific times e.g. activated on a day when diabetic clinics are run.

Can cover large numbers of respondents

The AC DC Study recruited 9,274 patients during a recruitment period of 3-weeks, from an eligible population of 10,895 patients. With potential future scalability of use, the Questionnaire Module could be used by England's 8,000 general practices that provide more than 340 million consultations every year (NIHR, 2019), resulting in the collection of an enormous amount of brief research data.

Specific questions can be asked

The automated check-in screen can be programmed to ask specific questions, however on recommendation from EMIS Health in this circumstance (EMIS health, 2019) and from our PPIE representatives, the number of questions asked of patients, whilst checking in for a booked appointment, was limited to just two. On discussion of this point with the Patient and Public Involvement and Engagement (PPIE) group, they were also in agreement that

asking only 2 or a maximum of 3 research questions would be appropriate, there would not be time for more than this and could impact on practice operationalisation.

No interviewer bias

The check-in screen is automated by the user, there is therefore no additional human interaction and so in this way, human interviewer bias is removed. However, the automated check-in screen is asking the research questions. If patients are unable to answer the questions appropriately, because they do not understand them, or they do not know how to answer them, this could indicate another form of 'interviewer bias' or 'IT competence bias'.

Effective for sensitive subjects

Whilst the automated check-in screen can be programmed to ask questions of a sensitive subject, how this would affect response rates is unknown and requires further research. Qualitative work is required from future research in this area, to provide a robust conclusion on acceptability of this AC DC methodology for collecting research data.

Complexity

As discussed in section 5.2, the automated check-in screen software allows routing (also known as skip-logic or branching) enabling a participant to be directed through a survey, based on the answers that they give. The applied logic to question formatting enables a user-friendly platform, whilst building in questions which are appropriate to responses. Where this is applied, quite a complex questionnaire could be conducted, which might only ask 2 or 3 questions of the end user, and which would otherwise be too complicated to design in a paper format.

Responses can be controlled

The AC DC methodology provides closed questions or those with fixed responses, from which participants can select an appropriate response. The use of routing can also be used

to control which questions can be seen by the patient, based on responses to previous questions.

Anonymity

All responses provided, using the automated check-in screen were recorded in the patients' electronic medical record. This is a setting functionality of the Questionnaire Module, however anonymity can be provided, with the use of different Questionnaire Module settings. These were not explored for the purposes of the AC DC Study, general practices most commonly use them to collect customer feedback data.

Contribution to clinical care

All responses provided, using the automated check-in screen, can be coded back into the patients' electronic medical record. In this way, the research data being collected is also contributing directly to clinical care. Once the patient enters the consultation, their responses may facilitate the appointment and make an efficient use of the time available.

Data monitoring

The Questionnaire Module software was programmed to deliver the two research questions in line with the study protocol. Data monitoring could be performed remotely by the Health Informatics Specialist and where any problems were identified, these could be rapidly rectified and recruitment could resume immediately. This ability to conduct real-time monitoring is another advantage of this AC DC methodology.

Missing data

When a participant answers questions in the order they appear on the check-in screen, missing data is less common. Participants however can't see what is coming next, as they can with a paper survey. Not being able to see the size of the task may increase the number of incomplete surveys. Whist the invitation poster displayed at the general practices did

state that there would be two research questions to be answered, a message on the check-in screen could have facilitated this further.

Other general advantages of survey data collection methodologies which the AC DC Study did not explore via the AC DC methodology of data collection, include; the use of visual aids, in-depth data collection, opportunities to clarify responses and the collection of follow-up data. These advantages were not deemed as either being appropriate or possible for the study, with the use of automated check-in screens to collect data, or for the purposes of the cross-sectional study aims.

7.1.1.2 Disadvantages

No opportunity to clarify or explore in-depth issues

Collecting data using the automated check-in screens allows for only brief questions and restricted responses. This creates an inability to clarify or explore participant responses further. The use of routing though, could be used to add some further detail based on responses.

Alternatively, if detailed data collection was required, patients could be screened for participation using the automated check-in screen, for subsequent contact then with another data collection methodology, for example a qualitative interview or a longer postal or online questionnaire. This could also improve resource efficiencies in the wider context of conducting research.

Gauging salience and context of responses

Similarly, the context of responses cannot be collected using an automated data collection tool without significantly impacting on the advantages of the method described or usual practice operationality. Patients may have limited time to complete the additional research questions or there may be patients waiting to use the check-in screen behind them. The

context of the waiting room environment or how the patient may have been feeling, is not captured using the AC DC methodology. We are though aware of when and where the research questions are answered, which creates a description of consistency, for the context of the physical environment that the data is captured in.

Restricts questionnaire length

With only two research questions asked, only limited data can therefore be collected using this AC DC methodology. The number of questions can certainly be increased, but this may impact on other advantages of this AC DC methodology discussed above. This tool is therefore ideal for capturing brief outcome measure data at the point of care, or for use in screening patients, for inclusion in a more detailed study later. Its key feature relates to the volume of participants that can take part in the study and the speed and efficiency with which data can be collected

Limited quantitative data

The AC DC methodology collects only a limited amount of quantitative data and would not be suitable for longer questionnaires. For certain research questions however, that are investigating more specific issues, that might need answering quickly and do not require in depth exploration at least initially, this is an efficient methodology. For example, the AC DC Study has identified that 39.0% of participants reported having *moderate* to *very severe* bodily pain during the past 4 weeks, a very prevalent health issue.

Missing data

Participants cannot see the length of the survey. Not being able to see the size of the task afore them, may increase the number of incomplete surveys. Unlike paper surveys, the questionnaire cannot be put down and then picked up again to finish off at a later time point. If data is not collected at the time of execution, then it will remain missing. Missing data however for the AC DC Study was low, with 96.2% of participants answering the first

question and 89.3% of participants answering the second question. A message on the check-in screen at the beginning, to clearly inform patients of the number of questions that they would be presented with, may also assist in the prevention of missing data.

Biases

Depending on the research question, the AC DC methodology could be affected by bias. This is explored further in section 7.5.

Other general disadvantages, of other survey data collection methodologies, that the AC DC methodology did not experience include: time consuming, obtaining relatively low response rates, and being subject to human interviewer bias.

The AC DC methodology to collect data, as with all methodologies, has advantages and disadvantages. It does however, represent a cost-effective (if used more than once), convenient and precise opportunity to collect data rapidly from significant numbers of participants, to answer certain types of research question.

Those practices operating General Practice System of Choice (GPSoC) EMIS Web were selected to participate as currently, only EMIS Web has the add-on facilities to enable the addition of bespoke, end-user defined questions. This could potentially, be a source of sampling bias, however the GPSoC used by the practice is unlikely to have any effect on how participants respond to research questions they are presented with. The participating general practices' EMIS Web system required Egton Automated Arrival facilities to include a Questionnaire Module and an automated arrivals check-in touchscreen. At two of the 9 participating practices, Egton Automated Arrival hardware facilities were installed at the practice in order that they could participate in the AC DC Study. At these two practices, the patients were not accustomed to using the automated check-in facilities (58.6% and 61.2% of patients using the automated check-in facilities).

Overall, 68.0% of all eligible patients used the automated check-in facilities, to check-in. This varied between 58.6% and 86.3% and reflects practice experience, with the lowest usage obtained from the two practices that required the Egton Automated Arrival hardware facilities fitting, in order to take part in the AC DC Study and so had little experience of its use.

7.1.2 Demographic differences

The literature informs us that women are more likely than men to consult a general practitioner (Eurostat, 2020), with more than a 10% difference in consultation rates. A study conducted by Orton and Gray identified that 61.0% of consultations were made by females (Orton & Gray, 2016). These findings concur with the AC DC Study. Given a total participating practice population of 84,976 patients, 50.8% were registered as female and 60.3% of all eligible patients with booked appointments during the recruitment period, were female. 61.0% of AC DC Study participants were female, as were 66.5% of non-participants, see Figure 6.3. These results provide evidence that there was no gender bias with the AC DC methodology, as those participating reflect the established consulter demographic norms.

7.1.3 Impact on general practice operationalisation

A negligible number of comments were made by participating practices reporting any impact on practice operationalisation, resulting from asking patients an additional two research questions at the point of automated check-in for a booked appointment.

The interactions, general practice systems and the physical environment of the waiting room area, all contribute to how well confidentiality can be maintained. It has been identified elsewhere, that sometimes patients initiate confidentiality breaches themselves in the general practice waiting room, as they are seemingly willing to disclose confidential

information (Scott, Dyas, Middlemass, & Siriwardena, 2007). There is a difference though in those patients that openly share information about themselves in such settings, compared to those that share information without wanting to. In order to avoid the latter group of patients feeling as though their confidentiality had been breached, usual general practice etiquette is for patients to 'hang back' when checking in or speaking with the receptionist. The feedback obtained from the PPIE group following a discussion on confidentiality, for the design of the AC DC Study, were invaluable. Despite the usual general practice etiquette for patients to 'hang back' and with the agreement that most practices advocate and advertise good privacy and personal space behaviour, the PPIE group were still concerned that patients behind in a queue, may overhear a conversation. The PPIE group therefore agreed that completing an automated check-in screen was probably more discreet than talking to a receptionist.

Another consideration was health and safety, particularly in terms of hygiene. Use of a touch screen in an environment where there may be contagious illnesses was a concern. The concerns however were considered proportional with those to include, opening of doors, holding onto railings etc., and then reduced as being insignificant by comparison. It was also noted that the majority of practices have hand gels and sanitisers available for patient use, which is also becoming a cultural norm for society.

7.2 Completion of research questions

Whilst this thesis concentrates on the methodological approach to collecting data in primary care, the AC DC Study investigated the degree of bodily pain patients had experienced over the last 4 weeks, with additional objectives to include investigating whether patients would be happy to be contacted about research of relevance to them.

7.2.1 'Bodily pain' research question

Moderate / *Severe* / *Very Severe* bodily pain over the last 4 weeks, was reported by 39.0% of participants, which is higher than the reporting of *No* bodily pain over the last 4 weeks, reported by 32.9% of participants. This finding is consistent with the literature. Whilst not directly mapping to the data but still of interest and comparison, results of a systematic review and meta-analysis of population studies, reviewing the prevalence of 'chronic pain' in the UK (Fayaz, Croft, Langford, Donaldson, & Jones, 2016) identified that, the prevalence of 'chronic pain' ranged from 35.0% to 51.3%. In addition, 61.5% of participants in a survey of self-reported 'joint pain' symptoms in UK primary care patients consulting for non-musculoskeletal (non-MSK) complaints, reported moderate/severe joint pain (Hider, et al., 2019) .

Moderate / *Severe* / *Very Severe* bodily pain over the last 4 weeks, was reported by 42.0% of females and 34.4% of males, and *No* pain was reported by 31.1% of females and 35.6% males. A finding of females reporting a higher intensity of pain was also reported by Fayaz *et al.*, 2016 where the prevalence of 'chronic pain' was consistently higher in female participants (37.0% to 51.8%) than in male participants (31.0% to 48.9%).

The AC DC Study asked patients about their experience of bodily pain over the last 4 weeks. The results of which have been compared with literature describing 'chronic pain', 'musculoskeletal pain' and 'joint pain'. Pain is a subjective measure and whilst the results do not directly map to the literature specifically, they allow for strong comparisons. Again and in parallel with the literature associated with pain, the AC DC Study identified an increasing prevalence of pain with increasing age. From the age of 50 years the prevalence of pain across severities, then continues at a similar prevalence.

Chronic pain has been identified as a significant health problem (Thompson, et al., 2021). The Royal College of General Practitioners (RCGP, 2021) report that chronic pain is a

presenting condition in around 22% of primary care consultations. This equates to 68.6 million general practice consultations (NHS Digital, 2019) per year. AC DC Study participants may not have been consulting for pain, however the study identified that 39.0% of patients report experiencing *Moderate* / *Severe* / *Very Severe* bodily pain. Patient experience of pain is clearly therefore a public health issue requiring further research.

Only 0.1% of participants answering the bodily pain question, reported *Severe* pain. This may reflect a true prevalence in the population studied but this low figure may have been related to the way the automated check-in screen displayed the 6 response options and is a significant learning point for future questionnaire formatting and delivery. Only 5 responses were visible on the screen making it look at first glance, as if there were only 5 response options. The scroll bar was situated to the right of the questions within the touch screen area, however without touching the screen and scrolling down, participants would not have seen the entire balanced scale of responses available, to select from. For future use of the automated check-in screen, where multiple choice responses are provided, a limit of 5 responses would be recommended.

7.2.1.1 Clinical utility of the 'bodily pain' research question

The AC DC Study placed no expectation on the consulting clinician to address the bodily pain severity reported by the patient using the automated check-in screen, when confirming attendance for their appointment. The clinician had access to this information, but whether this was discussed was left to their own discretion. Furthermore, data was not collected on how or whether this data was used during the attending appointment. To follow up on the utility of the pain intensity question, conducting qualitative research, on both participants and clinicians could further explore this in future research. It is also likely that a significant number of participants were both, attending for non-pain related reasons, and were not attending for an appointment with a doctor or a nurse but to see other health care practitioners for other reasons e.g. phlebotomy with a healthcare assistant. Whilst exploring

the clinical impact of the AC DC methodology, is beyond the scope of the AC DC Study, it is recognised that having a documented record of pain severity can be helpful to guide a patient's treatment, flag an un-recognised issue that might not be reported by a patient, reflect a level of physical functioning or be an early indicator of certain illnesses. It also may alert a clinician to an unrecognised pain problem that a patient had not thought important or relevant. Using this method of data collection embeds research entirely in clinical practice and represents an opportunity for research to have immediate impact on patient care and outcomes too.

7.2.2 'Contact about research' question

Almost 90% of participants completed the 'contact about research' question, with 46.9% of those answering the question, stating that they would be happy to be contacted about research of relevance to them. There was very little variation by practice or by gender in response, however less than 40% of those in the age groups 18 – 34 years and 80+ years confirmed they would be happy to be contacted about research of relevance. There may be a number of reasons for this. A negative perception of health increases with age (Eurostat, 2019), so whilst those participants in the age group 18 – 34 years may feel they have no need to take part in health research, those in the 80+ years age group may feel that they are now too old, to want to be involved in research.

Stigma and normalisation can also be used to explain the difference in those happy to be contacted about research of relevance in the youngest and oldest age groups. Those in the youngest age group may wish to remove themselves from being characterised by any involvement in health research. Those in the oldest age group may be normalising their current condition as a coping strategy that they fear they could disrupt, by involving themselves in any research (Bowling, 2014).

The ‘contact about research’ question did potentially provide patients with some control over how their data are used by the general practice. At the time the AC DC Study was recruiting, General Data Protection Regulation (GDPR) was a new legislative term, released in April 2018 under the Data Protection Act 2018. Patients may have felt empowered by their rights to protect how their personal details are used, resulting in 53.1% of participants not happy to receive any information about research of relevance to them. Whilst this statement may have been true at this point in time however, the health status of patients’ can change very quickly. Whilst the response to this question provides administrative efficiencies for the conduct of research today, the answer may need patient re-consideration over time, to reflect their on-going health status. It is recommended therefore that where this question is asked, a clause to retain the answer to this question and manage the patient data in accordance with response to this question, is updated approximately every 12 months.

Much of the existing literature in this area, concentrates on willingness to participate in research and focuses either on specific diseases or conditions, specific populations or specific research methodologies. In 2014, a survey of 3,000 people in England found that 89% would be happy to take part in a research study if they had a diagnosed disease or condition (Wise, 2014). Findings of a cross-sectional study conducted in the United States of America in 2016 however, match the findings of the AC DC Study and found that 47% of participants were willing to participate in research either as a healthy volunteer or if they had the disease being studied, 47% were unsure if they were willing to participate in research, and 6% were not willing to participate (Walter & Davis, 2016). The AC DC Study has only investigated willingness to be contacted about research of relevance, which could be considered as the stage before participation. There are so many factors influencing patient willingness to participate in research, some of which include: total amount of time required to participate; distance to be travelled to participate; amount of pain/discomfort to be endured; risks of the research study; inconvenience or burden; payments or incentives provided for participation; benefits of research for one’s own health outcomes; fears of being

‘experimented’ on; and benefits of the research for the health of others. With 46.9% of AC DC Study participants stating that they ‘would be happy to be contacted about research of relevance to them’, this could therefore be interpreted as being particularly low, given that some of the variables just described would then need to be considered and would subsequently lead to further attrition, once information about any future research of relevance had been received. However, if patients are willing to be contacted about research, they might also be willing to participate. An advantage of this, is that a further study could focus recruitment on only those ‘happy to be contacted’. It would be anticipated that in this scenario participation and thus response rates would be much higher and efficiencies would be incurred.

How the Corona Virus Disease (COVID 19) pandemic has affected the general publics’ willingness to participate in research will be discussed further in section 7.4.

7.2.3 Order of research questions

Design of a survey requires consideration and skill. There is widespread agreement that the first questions in a survey should be easy to answer, not sensitive or threatening (Sim & Wright, 2000) (Bowling, 2014). Questions that have been used successfully in previous studies are also advantageous for use (Coggon, Rose, & Barker, 2003). The length of the AC DC Study survey however, only provided limited ability for movement to the order in which, the research questions were asked. It was important that the language used for the research questions was as clear and simple for patients, as possible. The AC DC Study therefore, was designed with input from PPIE, to ensure this.

The ‘bodily pain’ question was adapted from previously used pain questions and then as described in section 5.4.1.2, the wording of the research questions, together with their associated options for completion, were then posed to the PPIE group. The PPIE group were asked to consider the wording and the order of the questions. On reading the question

options provided to them, there was cohesion of opinion that the first research question should be the ‘bodily pain’ question and the second research question be the ‘contact about research’ question. They considered that this would provide a smoother flow to the two questions, which were not particularly linked to each other.

The results of the study revealed that 10.7% of participants completed only the first, ‘bodily pain’ research question without answering the second question. Reasons for this could relate to; patients feeling pressure from a queue of patients behind them waiting to use the check-in screen; patients not appreciating that there would be no more than two research questions; or patients simply not knowing how to answer or wanting to commit either way to the second research question. 3.8% of participants, only completed the ‘contact about research’ question. Further analysis identified that 39.8% of these participants were happy to be contacted about research of relevance to them, which may therefore indicate that these participants were simply not comfortable answering research questions, especially in the waiting room environment.

The questions could have been asked in the reverse order, however given the PPIE feedback, this would not have been the intuitive order to ask the questions. More research on the impact that the order of the questions could have, would be interesting to conduct, especially given this very brief style of survey. Whilst the literature in this area provides a consistent consensus on an appropriate order of questions, future investigations could be conducted, using the AC DC methodology, such as changing the order of questions half way through the recruitment period or having a different order in a sample of practices. Real-time monitoring and remote access to the tool can enable flexibility in methods.

7.3 Time available for participation

Data monitoring, identified that one practice had a lower than expected questionnaire completion rate. Following investigation of the Questionnaire Module software settings at this practice, it was identified that the 'Time out' setting for question display time had been set at just 10 seconds. Identified on day 10 of recruitment, these settings were rectified and from then on, an expected recruitment rate was obtained.

Based on the experience described above, 10 seconds for completion of a research question was not long enough, for a patient to read, consider and answer a research question. The time limit enabled across all practices was 30 seconds per question. With a participation rate of almost 90%, it can be concluded that this provided enough time to answer each research question. The AC DC daily diaries, completed by practice administrative staff, did not indicate that the length of time the research questions were displayed for had affected practice operationalisation.

If the questions were displayed for any longer than 30 seconds, this may disrupt practice processes. Where the research questions were not completed, this may have been due to other factors such as language barriers, vision problems, illiteracy or unwillingness. Variables relating to the subject of the questions, the length of the questions and participants' health literacy level will also contribute to variation in the time it takes to check-in.

The participant invitation poster, displayed at close proximity to the automated check-in screen did inform patients that they would be asked two extra research questions at the point of check-in for their booked appointment. There was also a Participant Information Leaflet (PIL) available for patients to review. It is acknowledged that the PIL may not have been fully read prior to participation, however the PIL provided patients with details on how

they could withdraw or change any information provided for the study. In only one case, was it reported that a patient changed their mind on how they had answered a research question, which the practice administrator was able to amend on their behalf.

The time patients completed the automated check-in screen, in relation to their booked appointment time, did not affect whether or not they participated in the AC DC Study.

7.4 Corona Virus Disease 19 (COVID 19)

At the time of writing up this thesis and following the emergence of the Corona Virus Disease (COVID 19) in December 2019, many changes have occurred within the UK health system with the way in which healthcare is delivered, administered and managed. The UK government have also described the willingness of the UK public to participate in COVID-19 research as, "*inspiring*" (UK Government, 2020). In just over 8 months, 637,379 participants from across the UK have taken part in public health research investigating the effects of, and treatment for, COVID-19. This is remarkable, given that in the year 2019/2020, all research participation supported by the National Institute for Health Research (NIHR) Clinical Research Networks (CRNs) recruited just over 732,000 participants. This may indicate that public willingness to participate in research has improved, however it may also be a disease specific effect, inflated by public interest and the desire to contribute to a return to normality. Further research into the willingness of patients to be contacted about research of relevance to them would be interesting to conduct now, after completion of the AC DC Study, given the high profile and importance that health research has received following COVID-19.

Operationally, the number of telephone, email and virtual consultations have substantially increased, decreasing the number of in-practice face-to-face consultations (Park, Berlin, & Haines, 2020). Where in-practice consultations have existed, patients have been booked in

for appointments by administrative staff and automated check-in screens have not been used, due to the infection control risk associated with them.

The use of automated check-in screens to collect brief research data will not be a data collection methodology accepted or effectual within the near future unfortunately, but will undeniably return post pandemic.

7.5 Bias

Every method of data collection has both advantages and disadvantages; and implications for bias. Observations of patients are always fraught with bias, this is because humans do not always follow the process of what would be required to produce scientifically rigorous results (Fletcher & Fletcher, 2005). Many biases have been defined, however in clinical observations there are three main types; selection, information and confounding bias. How these relate to the results of the AC DC Study will now be explored.

7.5.1 Selection Bias

'Selection bias occurs as a result of errors in identifying the study population' (Stewart, 2016). If an analysis of a sample is conducted, with the intention of drawing conclusions about a population, selection bias would exist if the characteristics of the sample differed from that of the population. There are different types of selection biases, to include: sampling bias, allocation bias and responder bias. With the AC DC methodology of inviting patients to take part in research, sampling bias can be minimised to some extent, whereby we firstly acknowledge that only consulters can participate and then, the general practice encourages 100% of patients to check-in for their booked appointment. However, it cannot be completely removed, as 100% of the patients did not check-in for their appointment using the automated check-in screen and of those that did, 100% did not respond to the research questions generating non-response bias. The demographic data collected (age and gender)

does not highlight any demographic differences between the patients that did and did not use the automated check-in screens, however data on other factors which were not collected, such as ethnicity, literacy levels and language may have highlighted differences. Additionally, as the AC DC Study was conducted in general practices, the results presented are representative of a consulting population of primary care patients, but not necessarily of the general population.

Selection bias may also occur at the level of the general practice when using the AC DC method of data collection. This could occur where there is a mixture of 'research active practices' and 'non-research active practices' participating in a research study. Where the intention is to collect population level conclusions from data collected, bias could also occur if one geographical area does not have the GPSoC or the software facilities to participate. At research active practices, patients are used to participating in research, which could result in an increase in willingness to participate or conversely an unwillingness to participate due to research fatigue. Where technology is used variably across practices, this also affects those patients willing to participate in research depending on whether they are used to using technology, as the results of the AC DC Study have shown.

7.5.2 Information bias surveys

'Information bias affects the validity of health research. It originates from the approach that is utilized to obtain or confirm study measurements' (Althubaiti, 2016). Information bias can occur in the collection of data, specifically when the methods of measurement are dissimilar among participants. Other causes of information bias include: recall bias; social acceptability bias; recording bias, interviewer bias and misclassification bias.

Information bias would have occurred during the AC DC Study, if the general practice that had the 'Time out' setting for question display time set at just 10 seconds, continued

recruiting in this way. The data monitoring conducted for the study identified the error and as the setting was subsequently changed, this prevented information bias from continuing.

The AC DC methodology prevents 'social acceptability bias', whereby answers provided are influenced by knowing what future questions are going to arise. Future questions cannot be previewed and there is no function to allow the patient to go back and amend a previous answer

7.5.3 Confounding bias

'Confounding occurs when two factors are associated and the effect of one is confused with or distorted by the effect of the other' (Fletcher & Fletcher, 2005). If the outcome is directly related to the exposure, then no confounding bias is present. In the AC DC Study, the responses gained for the 'bodily pain' research question could have been affected by patients' recall or memory. Recall and memory in this case, may have contributed, as a confounding bias. The AC DC Study did seek appropriate PPIE advice on all patient facing documentation to include the wording of the research questions, to prevent any bias related to recall or memory. Comparisons of the data collected here, with that already published in the literature elsewhere, did not highlight any rogue findings.

In addition, as the invitation to participate in the research study and the subsequent participation was entirely automated, the delivery of the study remained consistent, preventing confounding bias in research question delivery.

7.5.4 Conclusions on bias

There is always the potential for bias in research and it would be extremely difficult to conduct research that was impervious to biases (Coggon, Rose, & Barker, 2003). The size and potential effect though of any bias must be considered and recognised to determine

whether it changes the results and the conclusions of a study. The biases considered for the AC DC Study have been discussed and where possible their impacts have been minimised. This assists in next, considering the reliability and validity of the results obtained from the study.

7.6 Reliability and validity

As previously described and defined in section 3.1, the less variation an instrument produces in repeated answers to a question, the higher its reliability (Bannigan & Watson, 2009). Reliability in this study is essentially the degree to which the automated check-in screens can collect stable and consistent results. Validity refers to how well the displayed research questions collect, what they are purported to collect.

A high degree of reliability in the data collected does not presuppose validity of the data. For this reason, a sample of general practices were included in this cross-sectional study. The high degree of validity obtained from the data collected across all participating general practices, could be interpreted to indicate a high degree of reliability about the data collected. In order to explore this further though and with more confidence, a more complex study would be required, employing additional data collection methodologies that were beyond the remit of the AC DC Study. Qualitative data collection on the two AC DC research questions would be required and compared with the automated data collection. Reliability could also be ensured, by repeating the research questions on a proportion of the cross-sectional study sample.

7.7 Further research

Government initiatives are continuously encouraging patient participation in health research. The National Institute for Health Research (NIHR) promote a campaign entitled,

"*I want to take part in a research study*", to provide easy access to research for patients (National Institute for Health Research, 2020).

Providing research which is accessible, regardless of patient age or health status must be the optimal way to encourage participation, as shown in the findings of the AC DC Study. The study found that, of those using the automated check-in facilities to confirm their attendance for a booked appointment, almost 90 per cent participated in the research study, with no variation by age of patient. Integrating research into routine practice with the AC DC methodology, is therefore an efficient and effective way to collect brief research data.

Designing a data collection methodology for research that could provide 100% participation would be a revolutionary achievement. Until then, the use of the most narrow range of possible tools is recommended (Axinn & Pearce, 2006). Whilst almost 90% of the patients invited to take part in the AC DC Study participated, 32% of all potentially eligible patients did not use the automated check-in screen to confirm attendance for their booked appointment and therefore could not participate. Another mode of invitation and possibly data collection would need to have been employed to ensure that 100% of patients with a booked appointment, were indeed invited to participate in the AC DC Study.

The acceptability of integrating research participation, as part of standard processes encountered by patients in primary care, cannot be exclusively answered from the results of this cross-sectional study. Acceptability of automated check-in screens to collect brief research data however, could be implied, based on the high response rates obtained here and the minimal impact on general practice operationalisation incurred. This does not directly assume that the methodology is acceptable though, and should only be interpreted as a crude proxy of acceptability. Whilst nine general practices were included in this study, had the source population from the 10th general practice or indeed, from another type of primary care setting differed, the results may have also differed. There is no agreed-upon

minimum acceptable response rate for a survey methodology of data collection, due to a variety of parameters making this impossible to predict. However, the greater response rate achieved, the more likely it is that, the entire range of views and measurements from the population being investigated, will be obtained. Further qualitative work, or a separate more detailed survey, is required to support the quantitative data collected and provide a robust conclusion on acceptability.

The introduction of research questions following check-in was a novel approach used for the AC DC Study. Should the AC DC methodology be used more often however, the impact on patients, especially the regular primary care consulters, may result in research fatigue. Research fatigue, has known significant impacts on patients' ongoing and future participation in studies (Ashley, 2020). Fatigue will also create further selection biases and negatively impact the representativeness of the findings. An advantage that the AC DC methodology has though, is that the questions are brief, limiting the burden on patients. Involvement in research, each time a patient attends their general practice for a primary care consultation however, may provide patients with the feeling that they are providing a positive contribution to health research and may encourage their involvement in more complex research studies. Additional quantitative and qualitative research would be needed to explore this further.

7.7.1 Future research questions

Whilst there are many definitions of public health, originating from different academic perspectives, the one point that is agreeable, is that it is a multidisciplinary approach to investigating the broad determinants of health (McClean, Bray, de Viggiani, Bird, & Pilkington, 2020) and focuses on entire populations rather than individual patients or diseases. The AC DC methodology to collecting data only allows for brief research questions to be asked. The results of the AC DC Study however, provide evidence that this

methodology can provide rapid data collection on key health issues, with potential for substantial scalability of use.

At scale, the brief data that could be collected could provide an insight to population level health issues. The AC DC methodology can be explored further too, in order to maximise the detail collected, with the use of routing. As such, the provided response to a first question could lead to different, and further investigative, follow-up questions. Researching sensitive topics could also be explored.

The AC DC methodology could be used to screen primary care consulters, in order to identify eligible research participants for more complex research studies. Development in the programming abilities of the software, could potentially activate the Questionnaire Module based on specific patient characteristics for example the disease/condition being investigated or certain demographics. Questions could then be asked to gauge suitability for inclusion in another study. This would facilitate a reduction in the process between potential participant identification and consent, using an automated methodology, creating efficiencies for the patient, the clinicians and researchers. This approach could be particularly useful in identifying patients with very specific or poorly coded conditions or situations (for example employment status).

These ideas are to be explored further with the overall aim of improving research efficiencies, minimising the time between potential participant identification and consent, and increasing patient participation in research. The clinical utility of the AC DC methodology can also be explored further. Patients using the AC DC methodology to provide answers to health questions as they attend, but prior to their consultation, allows immediate benefit to patients and clinicians. The responses patients provide are added directly into their electronic medical record and can then be used by the clinician for decision making, to highlight an issue or to direct treatment.

7.7.2 Digital innovations

With the COVID-19 pandemic initiating an extensive digital transformation in society, now is an ideal time to investigate other ways in which electronic research data can be captured quickly and efficiently, minus the resistance or inertia which we may have previously encountered. The use of text messaging Short Message Service (SMS) facilities are now increasingly being provided by general practices. Advances in this area can be seen by, the locally developed, use of simple telehealth systems such as Flo (The Health Foundation, 2020), that use text messages to support patients to manage their own health and wellbeing. The methodology of sending text messages (SMS) to patients needs also to be explored further to investigate whether this could provide answers to simple research questions, in much the same way as the AC DC methodology. Firstly, though a study to examine the SMS messaging reach, for the purposes of research, would be invaluable. With 96% of adults now owning a mobile phone (Ofcom, 2019), the research potential for data collection using this medium could be significant.

Improvements in the way in which healthcare data systems can interface with each other, will develop new insights to help health systems learn from each other and improve patient pathways (Rudrapatna & Butte, 2020). If the data interface between the GPSoC, SMS messaging and the AC DC methodology were linked, the potential for rapid patient identification, screening and consent for research could be extraordinary.

8 CONCLUSION

"It is good to have an end to journey toward; but it is the journey that matters, in the end."

— Ernest Hemingway

The aim of this thesis was to investigate the use of an automated check-in screen to collect brief research data from patients, whilst they are confirming their attendance for a booked appointment within a general practice setting. 89.2% of patients, presented with the opportunity, participated in the research study. 9 practices recruited 9,274 participants, with no significant demographic variances in participation or in responses, over a period of 3-weeks recruitment.

The 'clinical' research question of the cross-sectional study conducted was to estimate the number of patients reporting a degree of pain and the severities of pain. 96.2% (8,922) of participants answered the 'bodily pain' research question, "How much bodily pain have you had during the past 4 weeks?", providing a degree of pain. *Moderate* / *Severe* / *Very Severe* bodily pain over the last 4 weeks, was reported by 39.0% of participants. Patient experience of pain is clearly therefore a public health issue requiring further research and attention.

Another objective included, the 'non-clinical' research question of, estimating the number of patients that would be happy to be contacted about future research studies relevant to their health. Almost 90% of participants completed this question, with 46.9% stating that they would be happy to be contacted about research of relevance to them. Further research into the willingness of patients to be contacted about research of relevance to them would be interesting to conduct now, 2 years following the conduct of the AC DC Study, given the high profile and importance that the conduct of research has received following the Corona Virus Disease (COVID 19) pandemic.

The systematic literature search identified that there was very little evidence available in the literature, to describe the collection of research data from patients using automated devices, within primary care settings. Articles reviewed however, did provide some evidence to suggest that automated technologies, for use by patients, would be acceptable for data collection.

With almost a ninety percent participation rate in the AC DC study, of participants using automated check-in screens to provide brief research data, future use of the AC DC methodology is encouraging. The emergence of COVID 19 however, together with changes in the way in which healthcare is being delivered as a consequence, has culminated in the use of automated check-in screens not being an accepted or effectual method for data collection in the near future. It is anticipated though that there will be a future for the use of touch screen technology again and once this occurs and scalability of the AC DC methodology can be applied, participation by patients in research could become routine.

Choosing which data collection method to use when conducting research, remains a predicament for researchers. There are a spectrum of variables to consider when selecting the data collection methodology which is suitable for research however, whether the methodology selected and maybe even perfected for use, will continue to be practical over time, cannot be guaranteed, as this study has also shown with the emergence of COVID-19. During 2020 and as a result of the COVID 19 pandemic, technologies have radically transformed many aspects of our lives (Barnes, 2020). Our endeavour has encouraged the adoption of technologies and digitalisations in areas of our lives to include work, education, healthcare, entertainment and retail. My opinions for the future of data collection for the purposes of research concur with those of Barnes, who has identified, "*unprecedented new opportunities for research to impact practice*".

Whilst this thesis contributes to the research evidence, a concerted focus on further research in the use of automated technologies for the collection of participant research data is required in the post-COVID-19 world. With the COVID 19 pandemic initiating an extensive digital transformation in society (Livari, Sharma, & Ventä-Olkkonen, 2020), now is the ideal time to explore this opportunity further, minus the resistance or inertia which we may have previously encountered, by investigating other ways in which electronic research data can be captured quickly and efficiently. Increasing patient participation in research and minimising the time between identification of eligible participants and patient recruitment, being the main objectives. The ACDC methodology provides some opportunity for this. Accelerating this process allows for a rapid translation of research findings into a more reactive model of healthcare delivery.

My professional area of expertise, involves that of research operations. An opportunity to study for a Professional Doctorate in Health Sciences now provides me with an exciting prospect. I can build on the AC DC Study findings by exploring further, the use of primary care electronic systems for the identification of potentially eligible research participants and for the collection of research data using innovations in digitalisation.

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APPENDICIES

Appendix 1 Egton patient check-in

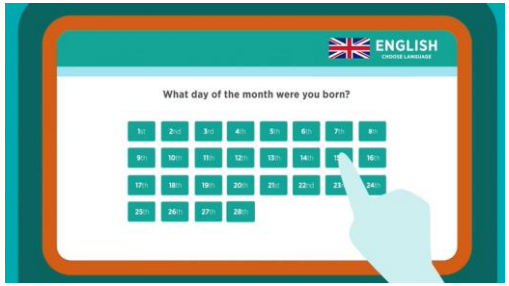
1)

2)

3)

4)

5)



6)

7)

8)

9)

Appendix 2 Participant Invitation Poster

ACDC
Automated Check-in Data Collection
STUDY

Keele UNIVERSITY

[NAME OF PRACTICE] is working with **Keele University** on a **research study** to collect some brief research information via the automated check-in screen.

Please take a **Participant Information Leaflet** for more details...

- If you are age 18 years or over, you will be asked 2 extra questions when checking-in for your booked appointment today.
- We would appreciate it, if you would be able to take a moment to answer them.
  If you don't wish to answer them, you will still be checked in as normal once the questions disappear.
- If you experience a problem checking in please see the reception staff.

IRAS Ref:248316_AC DC Invitation Poster_v2.0_23rd August 2018

Appendix 3 Participant Information Leaflet

Our commitment to protecting your information (data)

If you do decide to take part in this study, the information collected about you will be treated in strict confidence and in accordance with the Data Protection Act 2018. No personally-identifiable data will be sent to the sponsor, Keele University. Your GP will keep identifiable data as part of your medical records only.

You can find out more about how we use your information at: https://www.keele.ac.uk/informationgovernance/informationgovernanceforthepublic/

What will happen at the end of the study?

The results of this study will also be shared at national and international conferences and with publications in academic journals which are read by a large number of health professionals. You will not be identified individually in any poster, report or publication.

Results will also be posted on the iPCHS Twitter account and blog http://primarycarekeele.blogspot.com/

Who has reviewed the study?

To protect your interests, all research in the NHS is looked at by an independent group of people, called a Research Ethics Committee who are part of the Health Research Authority (HRA). This study has been reviewed and given favourable opinion by London – Westminster Research Ethics Committee 18/LO/1506.

What if there is a problem?

If you have a concern about any aspect of this study, you can discuss this with the study team. If you have questions about research studies in general, you can also discuss them with the healthcare professional you are about to see. Alternatively, you can contact NHS England on;
Telephone: 0300 311 2233
Email: england.contactus@nhs.net

Further contact details:

If you would like to know more about this study, or have any questions, please contact the AC DC Study Team on;

01782 734887
OR
primarycare.healthinformatics@keele.ac.uk
Office hours are Monday - Friday 9am - 4pm

Keele UNIVERSITY

ACDC Automated Check-in Data Collection STUDY

PARTICIPANT INFORMATION LEAFLET

You are being invited to take part in a research study called AC DC.

Thank you for taking the time to read the following information.

This leaflet explains why the study is being carried out, what is involved and how you can take part.

What is the purpose of the study?

The purpose of this study is to investigate patient acceptability, for providing brief research information whilst self-completing an automated check-in screen prior to any general practice consultation. Completion of the questions displayed, will provide us with information about the future use of automated check-in screens for the collection of research data. The research team have worked with patients and members of the public to ensure that this study is acceptable to patients, and the information being provided is easily understandable. Being involved in research can help to improve healthcare and patient choice.

Who is funding and organising the study?

This research is being funded and organised by the Research Institute for Primary Care and Health Sciences, at Keele University.

Why have I been asked to take part?

This study is taking place in several GP practices across North Staffordshire. You have been invited to take part in this study because you are 18 years of age or older and have a booked consultation with a Health Care Professional at this practice today.

What will I need to do if I take part?

If you would like to take part in the study, you will need to complete the automated check-in screen, to confirm your attendance for your booked appointment, then answer the additional two research questions which will automatically appear on the screen.

As many patients as possible are needed to complete the automated check-in screen over the next 3 weeks, in order that we can collect the brief research data. The two questions will take less than 1 minute of your time to complete.

If you do choose to take part and complete the additional two research questions displayed on the automated check-in screen, whilst confirming your attendance for your booked appointment, you are also free to withdraw or amend your responses at any time without giving a reason.

What should I do if I do **not** want to take part?

If you do not wish to answer the additional research questions which will be displayed following automated check-in, you can either select the 'Skip' option or, after a short delay, the research questions will disappear anyway and your confirmation of attendance for your booked appointment will be displayed.

If you complete the additional research questions and then wish to amend your answers, please let a member of general practice reception staff know or contact the study team. If you choose not to take part, this will not affect your current or future health care you receive.

What are the possible benefits of taking part?

Although there will be no direct benefit from taking part in this study, you will be helping us to develop new ways of collecting research data. Some people find it rewarding to take part in health research.

What are the possible risks of taking part?

There are no risks involved in taking part in this research study.

Appendix 4 REC Approval

NHS
Health Research Authority
London - Westminster Research Ethics Committee
4 Minshull Street
Manchester
M1 3DZ

Telephone: 0207 104 8012

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

30 August 2018

Professor Christian D Mallen
Interim Director, Research Institute for Primary Care and Health Sciences & NIHR Research Professor in General Practice
Keele University
Research Institute for Primary Care & Health Sciences
Keele University
Staffordshire
ST5 5BG

Dear Professor Mallen

Study title:	**Automated Check-in Data Collection Study**
REC reference:	**18/LO/1506**
Protocol number:	**1.0**
IRAS project ID:	**248316**

Thank you for your submission of 23 August 2018, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System, at www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be

registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" above).

Approved documents

The documents reviewed and approved by the Committee are:

Document	Version	Date
Covering letter on headed paper [AC DC covering letter]		07 August 2018
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [TWIMC Med Mal 2018-19]		23 July 2018
IRAS Application Form [IRAS_Form_07082018]		07 August 2018
Other [AC DC Ethics response]		23 August 2018
Other [AC DC Participant Information Leaflet]	2.0	23 August 2018
Other [AC DC Invitation Poster]	2.0	23 August 2018
Referee's report or other scientific critique report [Peer Review KJ]		26 July 2018
Referee's report or other scientific critique report [ReviewLetterRH]		30 July 2018
Research protocol or project proposal [AC DC Protocol]	1.0	11 July 2018
Summary CV for Chief Investigator (CI) [CV - Prof Christian Mallen]		25 July 2018
Summary, synopsis or diagram (flowchart) of protocol in non technical language [AC DC Study Summary]	1.0	27 July 2018
Summary, synopsis or diagram (flowchart) of protocol in non technical language [AC DC Study Flowchart]	1.0	27 July 2018

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol

- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

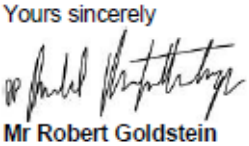
You are invited to give your view of the service that you have received from the Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:
http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance

We are pleased to welcome researchers and R & D staff at our RES Committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

18/LO/1506	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours sincerely



Mr Robert Goldstein
Chair

Email: nrescommittee.london-westminster@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to: Dr Clark Crawford, Keele University
Ms L Thakrar, NIHR Clinical Research Network (CRN): West Midands

Appendix 5 HRA Approval

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Professor Christian D Mallen
Interim Director, Research Institute for Primary Care and Health Sciences & NIHR Research Professor in General Practice
Research Institute for Primary Care & Health Sciences
Keele University
Staffordshire
ST5 5BG

Email: hra.approval@nhs.net
Research-permissions@wales.nhs.uk

24 September 2018

Dear Professor Mallen

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Automated Check-in Data Collection Study**
IRAS project ID:	**248316**
Protocol number:	**1.0**
REC reference:	**18/LO/1506**
Sponsor	**Keele University**

I am pleased to confirm that HRA and Health and Care Research Wales (HCRW) Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

How should I continue to work with participating NHS organisations in England and Wales?
You should now provide a copy of this letter to all participating NHS organisations in England and Wales, as well as any documentation that has been updated as a result of the assessment.

Following the arranging of capacity and capability, participating NHS organisations should **formally confirm** their capacity and capability to undertake the study. How this will be confirmed is detailed in the "*summary of assessment*" section towards the end of this letter.

You should provide, if you have not already done so, detailed instructions to each organisation as to how you will notify them that research activities may commence at site following their confirmation of capacity and capability (e.g. provision by you of a 'green light' email, formal notification following a site initiation visit, activities may commence immediately following confirmation by participating organisation, etc.).

It is important that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details of the research management function for each organisation can be accessed here.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within the devolved administrations of Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) has been sent to the coordinating centre of each participating nation. You should work with the relevant national coordinating functions to ensure any nation specific checks are complete, and with each site so that they are able to give management permission for the study to begin.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?
The document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

I am a participating NHS organisation in England or Wales. What should I do once I receive this letter?
You should work with the applicant and sponsor to complete any outstanding arrangements so you are able to confirm capacity and capability in line with the information provided in this letter.

The sponsor contact for this application is as follows:

Name: Dr Clark Crawford
Tel: 01782733371
Email: research.governance@keele.ac.uk

IRAS project ID	248316

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **248316**. Please quote this on all correspondence.

Yours sincerely

Kevin Ahmed
Assessor

Telephone: 0207 104 8171
Email: hra.approval@nhs.net

Copy to: *Dr Clark Crawford, Sponsor Contact, Keele University*
Ms L Thakrar, R&~D Contact, NIHR Clinical Research Network (CRN): West Midands

Appendix 6 Substantial Amendment REC Approval

NHS
Health Research Authority

London - Westminster Research Ethics Committee
4 Minshull Street
Manchester
M1 3DZ

Tel: 0207 104 8012

19 December 2018

Ms Sarah Lawton
Arthritis Research UK Primary Care Centre
Research Institute for Primary Care & Health Sciences
Keele University
Staffordshire
ST5 5BG

Dear Ms Lawton

Study title:	**Automated Check-in Data Collection Study**
REC reference:	**18/LO/1506**
Protocol number:	**1.0**
Amendment number:	**1**
Amendment date:	**12 November 2018**
IRAS project ID:	**248316**

The above amendment was reviewed by the Sub-Committee in correspondence.

Favourable opinion

This amendment saw revisions to the protocol and a change in the questions participants would be asked.

The Sub-Committee was unclear what exactly was being changed about data collection and processing and requested, via email, clarification of this.

> The researchers confirmed that the processing of data had not been changed in any way. A skip option had been added which allowed patients greater choice over participating or not. The additional data to be collected was the date and time of the appointment, the actual time of the consultation and what time the patient checked in.

The Sub-Committee appreciated the clarification and agreed the changes were acceptable.

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Covering letter on headed paper		26 November 2018
Notice of Substantial Amendment (non-CTIMP)	1	12 November 2018
Other [Amendment summary]		12 November 2018
Participant information sheet (PIS)	3.0	05 November 2018
Research protocol or project proposal	2.0	05 November 2018
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Flowchart]	2.0	05 November 2018

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

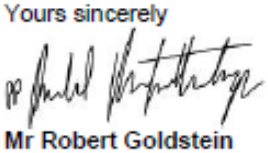
Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our Research Ethics Committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

18/LO/1506:	**Please quote this number on all correspondence**

Yours sincerely



Mr Robert Goldstein
Chair

E-mail: nrescommittee.london-westminster@nhs.net

Enclosures: List of names and professions of members who took part in the review

Copy to: Ms L Thakrar, NIHR Clinical Research Network (CRN): West Midands
Professor Christian D Mallen, Keele University
Dr Clark Crawford, Keele University

Appendix 7 Research question responses

General Practice	Gender		Both research questions		Pain question only		Contact question only	
		(n)	%	(n)	%	(n)	%	(n)
1	Female	(645)	82.0%	(529)	11.0%	(71)	7.0%	(45)
	Male	(454)	84.8%	(385)	11.5%	(52)	3.7%	(17)
2	Female	(674)	85.6%	(577)	9.1%	(61)	5.3%	(36)
	Male	(423)	88.2%	(373)	9.5%	(40)	2.4%	(10)
3	Female	(538)	74.5%	(401)	14.5%	(78)	11.0%	(59)
	Male	(365)	78.9%	(288)	15.9%	(58)	5.2%	(19)
4	Female	(547)	88.3%	(483)	8.4%	(46)	3.3%	(18)
	Male	(361)	85.9%	(310)	10.8%	(39)	3.3%	(12)
5	Female	(238)	82.4%	(196)	8.8%	(21)	8.8%	(21)
	Male	(133)	87.2%	(116)	10.5%	(14)	2.3%	(3)
6	Female	(1,432)	82.7%	(1,184)	11.3%	(162)	6.0%	(86)
	Male	(907)	86.9%	(788)	10.5%	(95)	2.6%	(24)
7	Female	(425)	82.4%	(350)	17.2%	(73)	0.5%	(2)
	Male	(283)	81.6%	(231)	18.4%	(52)	0.0%	(0)
8	Female	(697)	96.0%	(669)	4.0%	(28)	0.0%	(0)
	Male	(385)	96.6%	(372)	3.4%	(13)	0.0%	(0)
9	Female	(457)	87.1%	(398)	12.9%	(59)	0.0%	(0)
	Male	(310)	91.3%	(283)	8.7%	(27)	0.0%	(0)
Totals	Female	(5,653)	84.7%	(4,787)	10.6%	(599)	4.7%	(267)
	Male	(3,621)	86.9%	(3,146)	10.8%	(390)	2.3%	(85)
		(9,274)	**85.5%**	**(7,933)**	**10.7%**	**(989)**	**3.8%**	**(352)**

Appendix 8 Reported bodily pain during the past 4 weeks

General Practice	Gender	Age group	Response % (n)											
			None		Very mild		Mild		Moderate		Severe		Very Severe	
1 (n=1,037)	Female (n=362)	18 – 34 (n=65)	66.2%	(43)	15.4%	(10)	18.5%	(12)	26.2%	(17)	3.1%	(2)	0.0%	(0)
		35 – 49 (n=66)	42.4%	(28)	30.3%	(20)	27.3%	(18)	30.3%	(20)	25.8%	(17)	0.0%	(0)
		50 – 64 (n=91)	47.3%	(43)	22.0%	(20)	30.8%	(28)	61.5%	(56)	28.6%	(26)	0.0%	(0)
		65 – 79 (n=98)	48.0%	(47)	25.5%	(25)	26.5%	(26)	44.9%	(44)	21.4%	(21)	0.0%	(0)
		80+ (n=42)	69.0%	(29)	19.0%	(8)	11.9%	(5)	59.5%	(25)	23.8%	(10)	0.0%	(0)
		Total	**52.5%**	**(190)**	**22.9%**	**(83)**	**24.6%**	**(89)**	**44.8%**	**(162)**	**21.0%**	**(76)**	**0.0%**	**(0)**
	Male (n=437)	18 – 34 (n=40)	35.0%	(14)	17.5%	(7)	35.0%	(14)	12.5%	(5)	0.0%	(0)	0.0%	(0)
		35 – 49 (n=38)	44.7%	(17)	10.5%	(4)	21.1%	(8)	18.4%	(7)	5.3%	(2)	0.0%	(0)
		50 – 64 (n=131)	35.9%	(47)	11.5%	(15)	25.2%	(33)	18.3%	(24)	9.2%	(12)	0.0%	(0)
		65 – 79 (n=154)	40.9%	(63)	14.3%	(22)	14.9%	(23)	22.1%	(34)	7.8%	(12)	0.0%	(0)
		80+ (n=74)	43.2%	(32)	21.6%	(16)	10.8%	(8)	16.2%	(12)	8.1%	(6)	0.0%	(0)
		Total	**39.6%**	**(173)**	**14.6%**	**(64)**	**19.7%**	**(86)**	**18.8%**	**(82)**	**7.3%**	**(32)**	**0.0%**	**(0)**
	Totals		**35.0%**	**(363)**	**14.2%**	**(147)**	**16.9%**	**(175)**	**23.5%**	**(244)**	**10.4%**	**(108)**	**0.0%**	**(0)**
2 (n=1,051)	Female (n=638)	18 – 34 (n=163)	42.3%	(69)	9.8%	(16)	16.0%	(26)	17.8%	(29)	13.5%	(22)	0.6%	(1)
		35 – 49 (n=135)	31.9%	(43)	9.6%	(13)	17.8%	(24)	25.9%	(35)	14.8%	(20)	0.0%	(0)
		50 – 64 (n=190)	21.6%	(41)	8.9%	(17)	13.7%	(26)	26.8%	(51)	28.9%	(55)	0.0%	(0)
		65 – 79 (n=120)	15.0%	(18)	7.5%	(9)	10.8%	(13)	37.5%	(45)	29.2%	(35)	0.0%	(0)
		80+ (n=30)	20.0%	(6)	20.0%	(6)	6.7%	(2)	33.3%	(10)	20.0%	(6)	0.0%	(0)
		Total	**27.7%**	**(177)**	**9.6%**	**(61)**	**14.3%**	**(91)**	**26.6%**	**(170)**	**21.6%**	**(138)**	**0.2%**	**(1)**
	Male (n=413)	18 – 34 (n=56)	37.5%	(21)	12.5%	(7)	26.8%	(15)	17.9%	(10)	5.4%	(3)	0.0%	(0)
		35 – 49 (n=87)	23.0%	(20)	9.2%	(8)	16.1%	(14)	36.8%	(32)	14.9%	(13)	0.0%	(0)
		50 – 64 (n=114)	28.9%	(33)	6.1%	(7)	16.7%	(19)	39.5%	(45)	8.8%	(10)	0.0%	(0)
		65 – 79 (n=124)	33.9%	(42)	4.8%	(6)	12.9%	(16)	33.1%	(41)	15.3%	(19)	0.0%	(0)

General Practice	Gender	Age group	Response % (n)											
			None		Very mild		Mild		Moderate		Severe		Very Severe	
		80+ (n=32)	34.4%	(11)	15.6%	(5)	12.5%	(4)	25.0%	(8)	12.5%	(4)	0.0%	(0)
		Total	**30.8%**	**(127)**	**8.0%**	**(33)**	**16.5%**	**(68)**	**32.9%**	**(136)**	**11.9%**	**(49)**	**0.0%**	**(0)**
	Totals		**28.9%**	**(304)**	**8.9%**	**(94)**	**15.1%**	**(159)**	**29.1%**	**(306)**	**17.8%**	**(187)**	**0.1%**	**(1)**
3 (n=825)	Female (n=282)	18 – 34 (n=53)	52.8%	(28)	17.0%	(9)	30.2%	(16)	18.9%	(10)	11.3%	(6)	0.0%	(0)
		35 – 49 (n=68)	44.1%	(30)	14.7%	(10)	41.2%	(28)	26.5%	(18)	22.1%	(15)	0.0%	(0)
		50 – 64 (n=68)	50.0%	(34)	23.5%	(16)	26.5%	(18)	76.5%	(52)	25.0%	(17)	0.0%	(0)
		65 – 79 (n=73)	45.2%	(33)	28.8%	(21)	26.0%	(19)	56.2%	(41)	32.9%	(24)	0.0%	(0)
		80+ (n=20)	50.0%	(10)	25.0%	(5)	25.0%	(5)	25.0%	(5)	45.0%	(9)	0.0%	(0)
		Total	**47.9%**	**(135)**	**21.6%**	**(61)**	**30.5%**	**(86)**	**44.7%**	**(126)**	**25.2%**	**(71)**	**0.0%**	**(0)**
	Male (n=346)	18 – 34 (n=39)	41.0%	(16)	12.8%	(5)	23.1%	(9)	10.3%	(4)	12.8%	(5)	0.0%	(0)
		35 – 49 (n=43)	34.9%	(15)	20.9%	(9)	11.6%	(5)	16.3%	(7)	16.3%	(7)	0.0%	(0)
		50 – 64 (n=109)	36.7%	(40)	12.8%	(14)	13.8%	(15)	16.5%	(18)	20.2%	(22)	0.0%	(0)
		65 – 79 (n=121)	38.8%	(47)	14.9%	(18)	14.0%	(17)	19.8%	(24)	12.4%	(15)	0.0%	(0)
		80+ (n=34)	23.5%	(8)	17.6%	(6)	20.6%	(7)	23.5%	(8)	14.7%	(5)	0.0%	(0)
		Total	**36.4%**	**(126)**	**15.0%**	**(52)**	**15.3%**	**(53)**	**17.6%**	**(61)**	**15.6%**	**(54)**	**0.0%**	**(0)**
	Totals		**31.6%**	**(261)**	**13.7%**	**(113)**	**16.8%**	**(139)**	**22.7%**	**(187)**	**15.2%**	**(125)**	**0.0%**	**(0)**
4 (n=878)	Female (n=529)	18 – 34 (n=108)	41.7%	(45)	12.0%	(13)	15.7%	(17)	19.4%	(21)	11.1%	(12)	0.0%	(0)
		35 – 49 (n=128)	32.8%	(42)	9.4%	(12)	19.5%	(25)	29.7%	(38)	8.6%	(11)	0.0%	(0)
		50 – 64 (n=129)	22.5%	(29)	7.8%	(10)	14.0%	(18)	41.1%	(53)	14.0%	(18)	0.8%	(1)
		65 – 79 (n=116)	36.2%	(42)	6.9%	(8)	16.4%	(19)	23.3%	(27)	17.2%	(20)	0.0%	(0)
		80+ (n=48)	18.8%	(9)	4.2%	(2)	10.4%	(5)	35.4%	(17)	31.3%	(15)	0.0%	(0)
		Total	**31.6%**	**(167)**	**8.5%**	**(45)**	**15.9%**	**(84)**	**29.5%**	**(156)**	**14.4%**	**(76)**	**0.2%**	**(1)**
	Male (n=349)	18 – 34 (n=30)	56.7%	(17)	3.3%	(1)	20.0%	(6)	13.3%	(4)	6.7%	(2)	0.0%	(0)
		35 – 49 (n=73)	32.9%	(24)	8.2%	(6)	20.5%	(15)	27.4%	(20)	11.0%	(8)	0.0%	(0)
		50 – 64 (n=87)	34.5%	(30)	14.9%	(13)	12.6%	(11)	28.7%	(25)	9.2%	(8)	0.0%	(0)
		65 – 79 (n=119)	28.6%	(34)	14.3%	(17)	15.1%	(18)	30.3%	(36)	11.8%	(14)	0.0%	(0)

General Practice	Gender	Age group	Response % (n)											
			None		Very mild		Mild		Moderate		Severe		Very Severe	
		80+ (n=40)	42.5%	(17)	15.0%	(6)	20.0%	(8)	15.0%	(6)	7.5%	(3)	0.0%	(0)
		Total	**35.0%**	**(122)**	**12.3%**	**(43)**	**16.6%**	**(58)**	**26.1%**	**(91)**	**10.0%**	**(35)**	**0.0%**	**(0)**
	Totals		**32.9%**	**(289)**	**10.0%**	**(88)**	**16.2%**	**(142)**	**28.1%**	**(247)**	**12.6%**	**(111)**	**0.1%**	**(1)**
5 (n=347)	Female (n=217)	18 – 34 (n=44)	52.3%	(23)	6.8%	(3)	9.1%	(4)	25.0%	(11)	6.8%	(3)	0.0%	(0)
		35 – 49 (n=52)	30.8%	(16)	13.5%	(7)	23.1%	(12)	19.2%	(10)	13.5%	(7)	0.0%	(0)
		50 – 64 (n=57)	29.8%	(17)	3.5%	(2)	14.0%	(8)	29.8%	(17)	22.8%	(13)	0.0%	(0)
		65 – 79 (n=45)	22.2%	(10)	6.7%	(3)	17.8%	(8)	28.9%	(13)	24.4%	(11)	0.0%	(0)
		80+ (n=19)	36.8%	(7)	15.8%	(3)	21.1%	(4)	21.1%	(4)	5.3%	(1)	0.0%	(0)
		Total	**33.6%**	**(73)**	**8.3%**	**(18)**	**16.6%**	**(36)**	**25.3%**	**(55)**	**16.1%**	**(35)**	**0.0%**	**(0)**
	Male (n=130)	18 – 34 (n=23)	43.5%	(10)	4.3%	(1)	21.7%	(5)	21.7%	(5)	8.7%	(2)	0.0%	(0)
		35 – 49 (n=26)	38.5%	(10)	19.2%	(5)	19.2%	(5)	19.2%	(5)	3.8%	(1)	0.0%	(0)
		50 – 64 (n=31)	29.0%	(9)	29.0%	(9)	12.9%	(4)	29.0%	(9)	0.0%	(0)	0.0%	(0)
		65 – 79 (n=35)	48.6%	(17)	8.6%	(3)	8.6%	(3)	22.9%	(8)	11.4%	(4)	0.0%	(0)
		80+ (n=15)	26.7%	(4)	13.3%	(2)	13.3%	(2)	20.0%	(3)	26.7%	(4)	0.0%	(0)
		Total	**38.5%**	**(50)**	**15.4%**	**(20)**	**14.6%**	**(19)**	**23.1%**	**(30)**	**8.5%**	**(11)**	**0.0%**	**(0)**
	Totals		**35.4%**	**(123)**	**11.0%**	**(38)**	**15.9%**	**(55)**	**24.5%**	**(85)**	**13.3%**	**(46)**	**0.0%**	**(0)**
6 (n=2,229)	Female (n=1,346)	18 – 34 (n=269)	41.6%	(112)	13.0%	(35)	17.5%	(47)	19.7%	(53)	7.8%	(21)	0.4%	(1)
		35 – 49 (n=315)	39.0%	(123)	11.4%	(36)	16.5%	(52)	22.5%	(71)	10.5%	(33)	0.0%	(0)
		50 – 64 (n=334)	27.2%	(91)	11.1%	(37)	16.2%	(54)	28.1%	(94)	17.1%	(57)	0.3%	(1)
		65 – 79 (n=315)	29.8%	(94)	14.3%	(45)	10.5%	(33)	32.7%	(103)	12.7%	(40)	0.0%	(0)
		80+ (n=113)	28.3%	(32)	14.2%	(16)	15.0%	(17)	31.0%	(35)	11.5%	(13)	0.0%	(0)
		Total	**33.6%**	**(452)**	**12.6%**	**(169)**	**15.1%**	**(203)**	**26.4%**	**(356)**	**12.2%**	**(164)**	**0.1%**	**(2)**
	Male (n=883)	18 – 34 (n=79)	36.7%	(29)	17.7%	(14)	22.8%	(18)	12.7%	(10)	10.1%	(8)	0.0%	(0)
		35 – 49 (n=117)	30.8%	(36)	14.5%	(17)	23.1%	(27)	21.4%	(25)	10.3%	(12)	0.0%	(0)
		50 – 64 (n=230)	38.3%	(88)	15.7%	(36)	15.2%	(35)	20.9%	(48)	10.0%	(23)	0.0%	(0)
		65 – 79 (n=346)	36.1%	(125)	15.6%	(54)	15.6%	(54)	24.9%	(86)	7.8%	(27)	0.0%	(0)

General Practice	Gender	Age group	Response % (n)											
			None		Very mild		Mild		Moderate		Severe		Very Severe	
		80+ (n=111)	45.9%	(51)	6.3%	(7)	15.3%	(17)	27.0%	(30)	5.4%	(6)	0.0%	(0)
		Total	**37.3%**	**(329)**	**14.5%**	**(128)**	**17.1%**	**(151)**	**22.5%**	**(199)**	**8.6%**	**(76)**	**0.0%**	**(0)**
	Totals		**35.0%**	**(781)**	**13.3%**	**(297)**	**15.9%**	**(354)**	**24.9%**	**(555)**	**10.8%**	**(240)**	**0.1%**	**(2)**
7 (n=706)	Female (n=423)	18 – 34 (n=116)	39.7%	(46)	11.2%	(13)	26.7%	(31)	18.1%	(21)	4.3%	(5)	0.0%	(0)
		35 – 49 (n=101)	28.7%	(29)	7.9%	(8)	12.9%	(13)	31.7%	(32)	18.8%	(19)	0.0%	(0)
		50 – 64 (n=124)	25.8%	(32)	12.1%	(15)	11.3%	(14)	38.7%	(48)	11.3%	(14)	0.8%	(1)
		65 – 79 (n=59)	25.4%	(15)	5.1%	(3)	13.6%	(8)	37.3%	(22)	18.6%	(11)	0.0%	(0)
		80+ (n=23)	13.0%	(3)	21.7%	(5)	8.7%	(2)	30.4%	(7)	26.1%	(6)	0.0%	(0)
		Total	**29.6%**	**(125)**	**10.4%**	**(44)**	**16.1%**	**(68)**	**30.7%**	**(130)**	**13.0%**	**(55)**	**0.2%**	**(1)**
	Male (n=283)	18 – 34 (n=64)	39.1%	(25)	6.3%	(4)	18.8%	(12)	28.1%	(18)	7.8%	(5)	0.0%	(0)
		35 – 49 (n=58)	32.8%	(19)	12.1%	(7)	19.0%	(11)	25.9%	(15)	10.3%	(6)	0.0%	(0)
		50 – 64 (n=87)	18.4%	(16)	17.2%	(15)	20.7%	(18)	26.4%	(23)	17.2%	(15)	0.0%	(0)
		65 – 79 (n=61)	37.7%	(23)	6.6%	(4)	13.1%	(8)	27.9%	(17)	14.8%	(9)	0.0%	(0)
		80+ (n=13)	30.8%	(4)	15.4%	(2)	30.8%	(4)	23.1%	(3)	0.0%	(0)	0.0%	(0)
		Total	**30.7%**	**(87)**	**11.3%**	**(32)**	**18.7%**	**(53)**	**26.9%**	**(76)**	**12.4%**	**(35)**	**0.0%**	**(0)**
	Totals		**30.0%**	**(212)**	**10.8%**	**(76)**	**17.1%**	**(121)**	**29.2%**	**(206)**	**12.7%**	**(90)**	**0.1%**	**(1)**
8 (n=1,082)	Female (n=697)	18 – 34 (n=158)	44.9%	(71)	13.9%	(22)	16.5%	(26)	17.1%	(27)	6.3%	(10)	1.3%	(2)
		35 – 49 (n=185)	34.1%	(63)	8.6%	(16)	16.2%	(30)	26.5%	(49)	14.6%	(27)	0.0%	(0)
		50 – 64 (n=172)	23.3%	(40)	9.3%	(16)	14.5%	(25)	36.0%	(62)	16.3%	(28)	0.6%	(1)
		65 – 79 (n=131)	16.0%	(21)	13.0%	(17)	15.3%	(20)	40.5%	(53)	15.3%	(20)	0.0%	(0)
		80+ (n=51)	25.5%	(13)	9.8%	(5)	15.7%	(8)	29.4%	(15)	19.6%	(10)	0.0%	(0)
		Total	**29.8%**	**(208)**	**10.9%**	**(76)**	**15.6%**	**(109)**	**29.6%**	**(206)**	**13.6%**	**(95)**	**0.4%**	**(3)**
	Male (n=385)	18 – 34 (n=55)	34.5%	(19)	10.9%	(6)	30.9%	(17)	18.2%	(10)	5.5%	(3)	0.0%	(0)
		35 – 49 (n=69)	36.2%	(25)	11.6%	(8)	14.5%	(10)	30.4%	(21)	7.2%	(5)	0.0%	(0)
		50 – 64 (n=97)	30.9%	(30)	4.1%	(4)	19.6%	(19)	33.0%	(32)	12.4%	(12)	0.0%	(0)
		65 – 79 (n=138)	34.1%	(47)	6.5%	(9)	16.7%	(23)	28.3%	(39)	14.5%	(20)	0.0%	(0)

General Practice	Gender	Age group	Response % (n)											
			None		Very mild		Mild		Moderate		Severe		Very Severe	
		80+ (n=26)	42.3%	(11)	19.2%	(5)	3.8%	(1)	26.9%	(7)	7.7%	(2)	0.0%	(0)
		Total	**34.3%**	**(132)**	**8.3%**	**(32)**	**18.2%**	**(70)**	**28.3%**	**(109)**	**10.9%**	**(42)**	**0.0%**	**(0)**
	Totals		**31.4%**	**(340)**	**10.0%**	**(108)**	**16.5%**	**(179)**	**29.1%**	**(315)**	**12.7%**	**(137)**	**0.3%**	**(3)**
9 (n=767)	Female (n=274)	18 – 34 (n=71)	63.4%	(45)	15.5%	(11)	21.1%	(15)	32.4%	(23)	9.9%	(7)	1.4%	(1)
		35 – 49 (n=69)	47.8%	(33)	23.2%	(16)	29.0%	(20)	36.2%	(25)	14.5%	(10)	0.0%	(0)
		50 – 64 (n=68)	51.5%	(35)	22.1%	(15)	26.5%	(18)	58.8%	(40)	26.5%	(18)	0.0%	(0)
		65 – 79 (n=48)	56.3%	(27)	12.5%	(6)	31.3%	(15)	60.4%	(29)	25.0%	(12)	0.0%	(0)
		80+ (n=18)	55.6%	(10)	33.3%	(6)	11.1%	(2)	72.2%	(13)	27.8%	(5)	0.0%	(0)
		Total	**54.7%**	**(150)**	**19.7%**	**(54)**	**25.5%**	**(70)**	**47.4%**	**(130)**	**19.0%**	**(52)**	**0.4%**	**(1)**
	Male (n=310)	18 – 34 (n=48)	43.8%	(21)	16.7%	(8)	22.9%	(11)	10.4%	(5)	6.3%	(3)	0.0%	(0)
		35 – 49 (n=56)	30.4%	(17)	12.5%	(7)	16.1%	(9)	30.4%	(17)	10.7%	(6)	0.0%	(0)
		50 – 64 (n=85)	35.3%	(30)	16.5%	(14)	20.0%	(17)	16.5%	(14)	11.8%	(10)	0.0%	(0)
		65 – 79 (n=90)	37.8%	(34)	13.3%	(12)	11.1%	(10)	27.8%	(25)	10.0%	(9)	0.0%	(0)
		80+ (n=31)	38.7%	(12)	16.1%	(5)	16.1%	(5)	25.8%	(8)	3.2%	(1)	0.0%	(0)
		Total	**36.8%**	**(114)**	**14.8%**	**(46)**	**16.8%**	**(52)**	**22.3%**	**(69)**	**9.4%**	**(29)**	**0.0%**	**(0)**
	Totals		**34.4%**	**(264)**	**13.0%**	**(100)**	**15.9%**	**(122)**	**25.9%**	**(199)**	**10.6%**	**(81)**	**0.1%**	**(1)**
All practices (n=8,922)	Female (n=4,768)	18 – 34 (n=1,047)	46.0%	(482)	12.6%	(132)	18.5%	(194)	20.2%	(212)	8.4%	(88)	0.5%	(5)
		35 – 49 (n=1,119)	36.4%	(407)	12.3%	(138)	19.8%	(222)	26.6%	(298)	14.2%	(159)	0.0%	(0)
		50 – 64 (n=1,233)	29.4%	(362)	12.0%	(148)	17.0%	(209)	38.4%	(473)	20.0%	(246)	0.3%	(4)
		65 – 79 (n=1,005)	30.5%	(307)	13.6%	(137)	16.0%	(161)	37.5%	(377)	19.3%	(194)	0.0%	(0)
		80+ (n=364)	32.7%	(119)	15.4%	(56)	13.7%	(50)	36.0%	(131)	20.6%	(75)	0.0%	(0)
		Total	**35.2%**	**(1,677)**	**12.8%**	**(611)**	**17.5%**	**(836)**	**31.3%**	**(1,491)**	**16.0%**	**(762)**	**0.2%**	**(9)**
	Male (n=3,536)	18 – 34 (n=434)	39.6%	(172)	12.2%	(53)	24.7%	(107)	16.4%	(71)	7.1%	(31)	0.0%	(0)
		35 – 49 (n=567)	32.3%	(183)	12.5%	(71)	18.3%	(104)	26.3%	(149)	10.6%	(60)	0.0%	(0)
		50 – 64 (n=971)	33.3%	(323)	13.1%	(127)	17.6%	(171)	24.5%	(238)	11.5%	(112)	0.0%	(0)
		65 – 79 (n=1,188)	36.4%	(432)	12.2%	(145)	14.5%	(172)	26.1%	(310)	10.9%	(129)	0.0%	(0)

General Practice	Gender	Age group	Response % (n)					
			None	Very mild	Mild	Moderate	Severe	Very Severe
		80+ (n=376)	39.9% (150)	14.4% (54)	14.9% (56)	22.6% (85)	8.2% (31)	0.0% (0)
		Total	**35.6% (1,260)**	**12.7% (450)**	**17.3% (610)**	**24.1% (853)**	**10.3% (363)**	**0.0% (0)**
	Totals		**32.9% (2,937)**	**11.9% (1,061)**	**16.2% (1,446)**	**26.3% (2,344)**	**12.6% (1,125)**	**0.1% (9)**